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Guilt, dysfunctional thought processes and depression in caregivers of people with dementia

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Content and Format

Chapter 1 (Systematic Review) adheres to the author guidelines issued for Clinical Psychology and Psychotherapy (Appendix 1). A reference list is provided at the end of this chapter, which contains all of the references cited within the systematic review.

Chapter 6 (Journal Article) adheres to the author guidelines issued for International Psychogeriatrics (Appendix 2). A reference list is provided at the end of this chapter, which contains all of the references cited within the journal article.

Chapters 2 – 5 adhere to style guidelines issued by the British Psychological Society (2004). A reference list is provided at the end of the thesis, which contains all of the references cited within the whole thesis portfolio.

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Abstract

Background: Leading researchers have called for more sophisticated research designs in caregiver intervention research; by using theoretically grounded interventions, considering the likely mechanism of action and using appropriate outcome measures. This thesis comprises a systematic review which evaluates the match between psychosocial interventions for dementia caregiver burden and the burden measure used to evaluate them and an empirical study which tests the psychometric properties of two caregiving outcome measures developed in Spain (Caregiver Guilt Questionnaire - CGQ and Dysfunctional Thoughts about Caregiving Questionnaire - DTACQ). The empirical study also considers the role of guilt and cognition (conceptualized as dysfunctional thoughts in Cognitive Behavioural Therapy and cognitive fusion in Acceptance and Commitment Therapy) in predicting depression in dementia caregivers.

Systematic review: Results for the effectiveness of psychosocial interventions to reduce dementia caregiver burden are mixed. Caregiver burden is inconsistently defined and measured, which may contribute to the mixed results. This review sought to systematically evaluate the match between psychosocial interventions for dementia caregiver burden and the burden measure used to evaluate them. A systematic search identified 15 studies using the 22 item Zarit Burden Interview as an outcome measure. A systematic review using specified quality criteria indicated a low level of congruence between the content of the psychosocial interventions and the content of the Zarit Burden Interview used to evaluate the interventions in the majority of studies.

Methods: 221 informal familial dementia caregivers completed a cross sectional postal questionnaire survey.

Results: Using exploratory factor analysis, the factor structures of the CGQ and DTACQ identified in the Spanish development studies were replicated in this study. Adequate internal consistencies were found for both scales. Convergent validity was established for the CGQ with the measures of guilt and depression. The DTACQ correlated positively with general dysfunctional attitudes and negatively with amount

of support received as predicted, but did not correlate significantly with depression. A multiple regression analysis identified caregiver guilt and cognitive fusion, but not dysfunctional attitudes as significant predictors of depression in dementia caregivers.

Conclusion: The CGQ appears to be a reliable and valid measure of caregiver guilt in a British population of dementia caregivers, although further research is recommended to develop the DTACQ. The relative strength of cognitive fusion as a predictor of caregiver depression suggests that the way in which an individual relates to their thoughts should be tested as a mechanism of change in dementia caregiver interventions.

1 Systematic Review: Correspondence between intervention and outcome measurement in studies of dementia caregiver burden.

1.1 Abstract

It is well established that dementia caregivers experience significant burden and are at a greater risk of physical and psychological morbidity than their non-caregiving peers. Results for the effectiveness of psychosocial interventions to reduce caregiver burden are mixed. Caregiver burden is inconsistently defined and measured, which may contribute to the mixed results. This review sought to systematically evaluate the match between psychosocial interventions targeting dementia caregiver burden and the burden measure used to evaluate them. 15 studies were included, which targeted informal familial dementia caregivers and were evaluated using the Zarit Burden Interview (ZBI). Congruence between intervention and outcome measures was found to be low for 14/15 studies. The methodological quality of studies was also poor for the majority of studies. The psychological wellbeing and social life components of the ZBI were most commonly targeted by the interventions. No studies addressed the physical health, financial or relationship between care recipient and caregiver components of the ZBI. There was limited reporting of the definition of burden used or of a theorised mechanism of change. It is possible that effective interventions are being classed as ineffective and are unavailable to caregivers in part because of a poor match between the intervention and burden outcome measure. Future research studies should clearly specify the conceptualisation of caregiver burden used and use a measure of caregiver burden which corresponds to this.

1.1.1 Key words: burden, caregiver, carer, dementia, congruence, outcome

1.2 Introduction

Approximately 700,000 people live with dementia in the UK (Alzheimer's Society, 2007), two thirds of whom live in the community either alone or with family members (Alzheimer's Society, 2008). Family caregivers provide large amounts of care for people with dementia, saving the state approximately £6 billion per year (Alzheimer's Society, 2007). However, the burden of caring for someone with dementia can be significant; as well as having social and financial implications for the caregiver, caregivers suffer higher levels of depression and anxiety, greater incidence of physical health problems and a shortened life expectancy (Schulz, Martire & Klinger, 2005).

Caregiver burden is defined in a variety of ways: George and Gwyther (1986) highlighted “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults” (p.253). Thomson and Doll (1982), however suggest that burden can be usefully differentiated as subjective and objective burden; that is, idiosyncratic internalised negative feelings aroused in caregivers undertaking caring activities and the disruption to other areas of life caused by caring events and activities. Poulshock and Deimling (1984) argued that for conceptual clarity, burden should solely refer to caregiver distress in dealing with the care recipient impairments, with what other authors (Montgomery, Gonyea & Hooyman, 1985; Thomson & Doll, 1982) termed ‘objective burden’ reframed as ‘impact of caregiving’. However, as highlighted by Lawton *et al.* (1989), it is questionable whether it is possible to differentiate objective burden from subjective burden. Items included in burden measures referring to objective burden frequently rely on the caregiver's *appraisal* of the impact of caregiving rather than on the frequency, presence or absence of a particular behaviour in itself, therefore introducing a subjective or appraisal element into the measurement of objective burden.

Drawing on Lazarus and Folkman's (1984) stress process model, in which a potential stressor arouses the appraisal of its threat (primary appraisal) and then appraisal of the individual's ability to cope (secondary appraisal), Lawton *et al.* (1991) reframed burden as part of the secondary appraisal process, termed 'caregiving appraisal'. This refers to evaluative cognitive and affective responses to the demands of caregiving and the caregiver's ability to respond to these demands. Lawton *et al.* (1991) argued the two most important categories of caregiving appraisal are caregiving satisfaction, defined as "subjectively perceived gains from desirable aspects of, or positive affective returns from, caregiving" (p.182), and subjective caregiver burden, defined as "the perception of psychological distress, anxiety, depression, demoralization, and generalized loss of personal freedom attributed directly to caregiving" (p.182).

Even though Lawton *et al.* (1991) have clearly embedded their definition of burden within a theoretical framework, subjective caregiver burden still encompasses a wide variety of emotions, cognitions and a sense of role strain, as in other definitions of burden. This is somewhat at odds with the general approach of stress process researchers to precisely define different components of the stress process (Braithwaite, 1992) and the broad definition of burden continues to present a significant challenge for researchers looking to measure burden in a reliable and comprehensive manner.

The lack of agreement regarding the definition of caregiver burden is reflected in the myriad of burden measures used in research studies. Whalen and Buchholz (2009) identified 74 measures of caregiver burden in the literature, 17 of which had been developed for dementia caregivers. These 17 measures ranged between 14 and 42 items in length and varied in terms of the robustness of their development and their structure. Across the measures the structure of caregiver burden was conceptualized as containing one, two, three, four, five and eight different aspects of burden.

Systematic reviews and meta-analyses of the effectiveness of psychosocial interventions at reducing dementia caregiver burden have produced mixed results, from significant but small effects (e.g. Pinquart & Sorensen, 2006) to non significant effects (e.g. Brodaty, Green & Koschera, 2003). Leading researchers (e.g. Brodaty, 2007; Knight, Lutzky & Macofsky-Urab, 1993; Mittelman, 2008; Zarit & Femia 2008) have highlighted key issues that must be addressed in order to optimize psychosocial intervention studies, such as ensuring interventions are derived from theoretical models and the careful selection of outcome measures. However, given the variety of conceptualizations of burden and measures of burden, it is questionable how well these issues are addressed in studies of interventions seeking to reduce caregiver burden. A poor match between the intervention and the measure of burden used to evaluate it could be a contributing factor to the failure to find a significant effect for the intervention.

This review seeks to systematically evaluate the congruence between psychosocial interventions designed to reduce dementia caregiver burden and the components of the burden measure used to evaluate them. The methodological quality of individual studies will be considered, however the main focus of this review is the evaluation of congruence.

1.3 Methods

1.3.1 Search strategy

A systematic review of the literature was undertaken. Keywords used were based on those used in previous systematic reviews and meta analyses. The following search terms were used: carer* OR caregiv* AND dementia OR Alzheimer* AND evaluation OR trial OR intervention OR program* OR support OR training AND burden. Databases searched were Medline (1946 – March week 1 2012), Embase (1980 – week 11 2012), Cinahl (1937 – week 11 2012) and PsycInfo (1806 – week

11 2012). The start of the search was set as the earliest year available on each database.

1.3.2 Inclusion and exclusion criteria

Inclusion criteria are as follows: psychosocial intervention studies which recruited informal caregivers of persons with dementia living in the community; the intervention was evaluated using a validated, published measure of caregiver burden; burden measures must have been used at pre- and post-intervention intervals; and studies which were published in the English language in a peer-reviewed journal.

Exclusion criteria are as follows: the use of a non-validated abbreviated form of a published measure of caregiver burden; and the use of a validated measure of caregiver burden in a non-validated translated format.

1.3.3 Search results

The search strategy yielded 3947 results, the titles and abstracts of which were reviewed using the criteria described above, resulting in 186 potential papers for inclusion. After duplicates were removed, the full text for the remaining 86 papers were sourced to confirm eligibility, from which a further 47 papers were excluded (see Figure 1 for reasons for exclusion).

Ten different published measures of burden were used within the remaining 39 studies. The most commonly used measure was the 22 item Zarit Burden Interview (ZBI) (Zarit, Reever & Bach-Peterson, 1980), used in 15 studies, followed by the 12 item ZBI, used in eight papers, followed by the Caregiver Burden Inventory (Novak & Guest, 1989), used in five studies. The remaining seven burden measures were used in only one or two studies each.

Assessment of congruence requires the content of the burden measure, either its conceptual or factor structure, to be compared to the content of the intervention which the measure is being used to evaluate. As can be seen from the review of burden measures by Whalen and Buchholz (2009), burden outcome measures vary greatly in their conceptual and factor structure. Therefore, it was not thought to be feasible with the constraints of this review to assess the congruence of multiple measures and interventions, without making unwieldy comparisons between numerous different conceptual structures of caregiver burden. The wisdom of assessing the congruence of some measures and interventions may also be called into question when the reliability and feasibility of many measures of caregiver burden has not been adequately tested (Whalen & Buchholz, 2009). As the most commonly used measure of caregiver burden within the search results of this review, the 22 item ZBI, is also the most commonly used burden measure within the wider literature (Knight, Fox & Chou, 2000) it was decided that it would be highly relevant to both researchers and clinicians to focus solely on the congruence of this predominant measure and the interventions which it is used to evaluate. Only those papers (n = 15) using the full ZBI were included in this review.

Figure 1 illustrates the search process. The authors of each paper were contacted to request study protocols if available, except for Gendron *et al.* (1996), for whom up to date contact details could not be sourced. Six authors responded (Coen, O'Boyle, Coakley & Lawlor, 1999; Gitlin & Winter, 2007; Hébert, Leclerc, Bravo, Girouard & Lefrançois, 1994; Kahan, Kemp, Staples & Brummel-Smith, 1985; Ostwald, Hepburn, Caron, Burns & Mantell, 1999; Tremont, Davis, Bishop & Fortinsky, 2008), with four providing protocols or other information with a description of the intervention for evaluation.

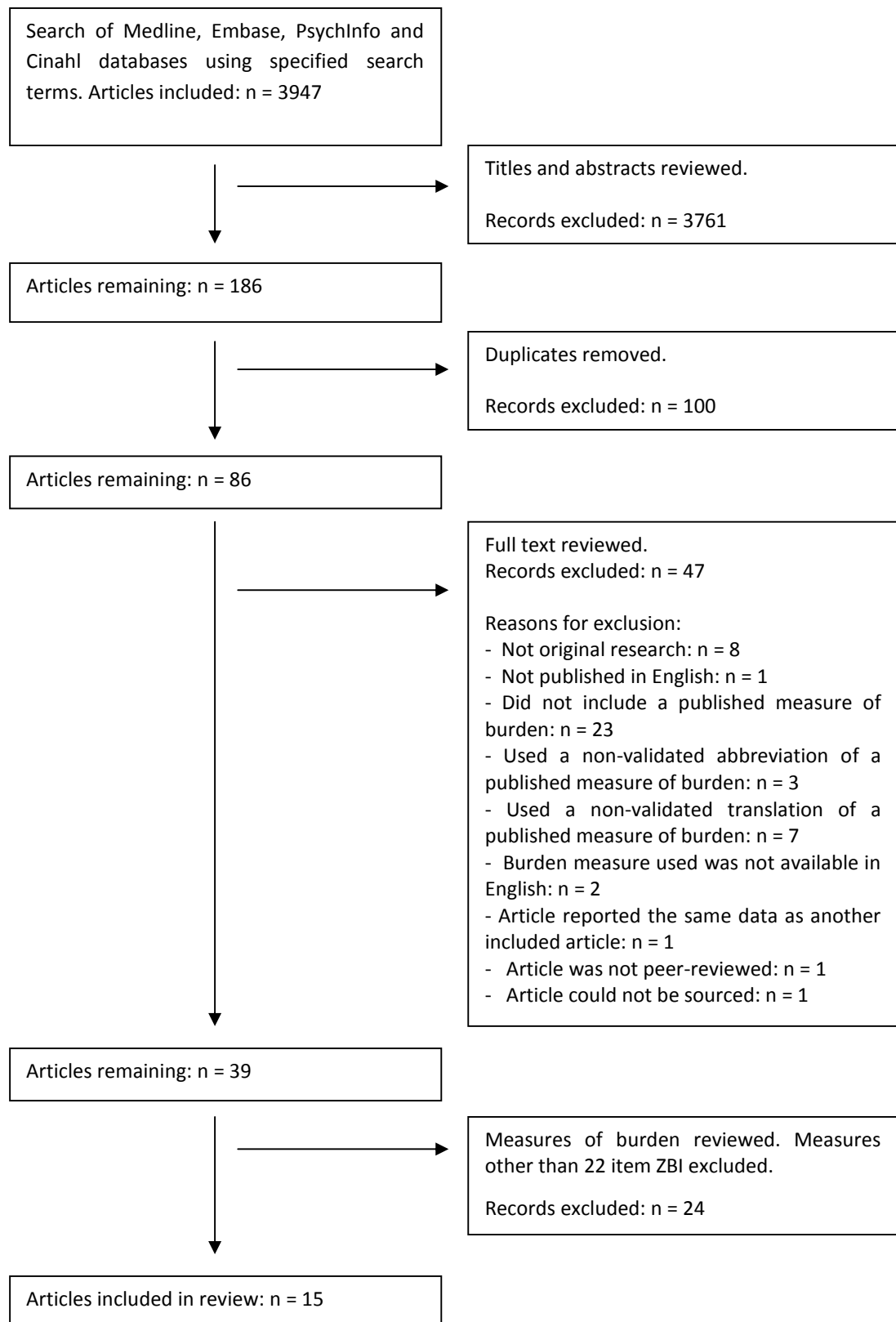


Figure 1: Systematic search process

1.3.4 Quality indicators - methodology

As study design was not an exclusion criteria within this review, the quality criteria used needed to be applicable to a wide variety of study designs, including quasi-experimental. The methodological quality of each study was evaluated using quality criteria based on those within SIGN 50: A guideline developer's handbook (2008). The SIGN quality criteria are based on the MERGE (Method for Evaluating Research and Guideline Evidence) checklists developed in Australia (Liddle, Williamson & Irwig, 1996), which have been used in systematic reviews published in peer-review journals internationally. The quality criteria covered key aspects of selection, detection and attrition biases and statistical issues (see Table 3 for criteria and ratings and Appendix 3 for a sample proforma). Outcome ratings were assigned a points value; criteria 1, 2, 3, 4 and 7 could be rated as well covered (2 points), adequately addressed (1 point), poorly addressed, not addressed, not reported or not applicable (all 0 points). Criteria 5, 6, 8 and 9 had a yes/no response format (yes yields 1 point, no, not applicable or not reported yields 0 points). Overall, randomized controlled trials could receive a maximum of 14 points, non-randomised controlled trials a maximum of 10 points, and uncontrolled trials a maximum of 3 points. A higher score indicates better methodological quality. Percentages were calculated to facilitate a comparison of total methodological quality across studies.

1.3.5 Quality indicators - congruence

Studies were evaluated for degree of congruence between the intervention and the burden outcome measure used. A systematic review of the literature was undertaken to search for methods of assessing congruence. The following search terms were used: congruence OR consistency OR match OR concordance AND intervention OR outcome OR measure. Results were limited to the English language. Databases searched were OVID Medline (1946 – July week 3 2012) and Embase (1974 – week 30 2012). One paper was found which had evaluated congruence between interventions and another factor (Shaw, Linton & Pransky, 2006). This study

examined the congruence between risk factors and intervention strategies for low back pain. The framework used by Shaw *et al.* (2006) assesses congruence at two levels: the level of content (whether the intervention was designed to target a specific risk factor) and the level of theory (whether there was a theoretical mechanism by which the intervention would reduce a specific risk factor). Rather than produce an idiosyncratic method for this review, the structured questions used by Shaw *et al.* (2006) were thought to be appropriate, with the wording modified to suit the caregiving literature (see Appendix 3 for a sample proforma). The following three questions were used:

1. Was the intervention specifically designed with the intent of affecting this aspect of caregiver burden as measured by ZBI? This question was used five times to evaluate the congruence between the intervention and each of the five components of the ZBI. One point was awarded for congruence between the intervention and each of the five components of the ZBI (giving a maximum of five points).
2. Do the authors explicitly report a reasonable theoretical explanation or mechanism to suggest how the intervention would affect this aspect of caregiver burden as measured by ZBI? This question was used five times to evaluate the congruence between the intervention and each of the five components of the ZBI. One point was awarded for congruence between the intervention and each of the five components of the ZBI (giving a maximum of five points).
3. Did the intervention significantly reduce the total ZBI score? This question was not assigned a score.

Items in the ZBI were developed from Zarit *et al.*'s clinical experience and the research literature. Zarit *et al.* (1980) designed the ZBI to cover the five areas most commonly perceived as problematic by caregivers: caregiver's health, psychological wellbeing, finances, social life and the relationship between the caregiver and care recipient. To assess congruence in each study the first two questions were used to

evaluate the congruence between the intervention and caregiver's health, psychological wellbeing, finances, social life and the relationship between the caregiver and care recipient. Each study could achieve a maximum of 10 points for congruence. Following Shaw *et al.* (2006), scores of 0-3 were classified as low congruence, 4-6 as moderate congruence and 7-10 as high congruence.

1.3.6 Inter-rater reliability - methodology

The lead author (LR) and one supervisor (KQ) independently evaluated the methodological quality of all studies ($n = 15$). An inter-rater reliability analysis using the Kappa statistic was performed to determine consistency between raters. For methodological quality, excellent inter-rater agreement was found: Kappa = 0.85 ($p < .001$). Discrepancies were then reviewed and discussed until a consensus was reached.

1.3.7 Inter-rater reliability - congruence

The lead author (LR) and one supervisor (KQ) also independently evaluated the congruence between study interventions and ZBI for all studies ($n = 15$). For congruence, fair agreement was found: Kappa = 0.55 ($p < .001$). Discrepancies were reviewed and discussed until a consensus was reached.

1.4 Results

1.4.1 Study characteristics

The 15 papers reviewed are described in Table 1. Data and statistical analyses not relevant to the purpose of this systematic review are not reported here. Five studies reported that burden was a primary outcome measure (Dang *et al.*, 2008; Lam *et al.*, 2010; Martin-Carrasco *et al.*, 2009; Tremont *et al.*, 2008; Winter & Gitlin, 2007),

and one (Hébert *et al.*, 2003) reported that it was a secondary outcome measure. The majority of studies (n=9) did not report whether burden was a primary or secondary outcome. There appeared to be an effect of publication date in relation to this; of the seven studies published before 2000, none reported whether burden was a primary or secondary outcome measure. Of the eight studies published from 2000 onwards, all studies except two (Hepburn, Lewis, Sherman & Tornatore, 2003; Hepburn *et al.*, 2005) reported whether burden was a primary or secondary outcome measure. The majority (n=10) of studies employed randomized controlled trial designs; one study utilized a non randomized controlled trial design (Brodaty, Roberts & Peters, 1994) and a further four (Coen *et al.*, 1999; Dang *et al.*, 2008; Hepburn *et al.*, 2003; Kahan *et al.*, 1985) utilized an uncontrolled, within subjects, pre- and post-intervention comparison (before and after comparison, Higgins & Green, 2011).

Table 1: Summary of reviewed papers

| Study | Design ¹ | Sample | Burden as primary or secondary outcome | Other caregiver outcomes measured ² | Intervention |
|---|---------------------|---|--|--|---|
| Kahan <i>et al.</i> , 1985, USA | BA | N = 40 (age range 16-77) 47.5% spousal caregivers | Not reported | ZSDS, <i>Dementia Quiz</i> | Education and support group. |
| Goodman, 1990, USA | RCT | N = 81 (mean age 65.9, SD=11.7) 72.5% spousal caregivers 75% female | Not reported | MPBC, MHI, PSSCSC, <i>Dementia Quiz</i> , <i>Social Support – frequency & satisfaction</i> | Peer to peer telephone support network. |
| Brodaty <i>et al.</i> , 1994, Australia | NRCT | N = 81 (mean age 64.3, SD=10.6) 75% spousal caregivers 77% female | Not reported | GHQ-30, SWLS, PANAS, <i>Dementia Quiz</i> | Education and skills training group. |
| Hébert <i>et al.</i> , 1994, Canada | RCT | N = 41 (mean age 61.1, SD=13.3) 68% spousal caregivers 63% female | Not reported | BSI, ADKT, RMPBC | Education and support group. |
| Gendron <i>et al.</i> , 1996, Canada | NRCT | N = 35 (mean age 66.2, SD=9.5) 100% spousal caregivers 66% female | Not reported | MPBC, HSC, ATQ, JCS, RAI, DAS, <i>Program evaluation</i> | Cognitive-behavioural therapy group. |
| Coen <i>et al.</i> , 1999, Ireland | BA | N = 32 (mean age 56.9) 46% spousal caregivers 71.5% female | Not reported | SEIQoL-DW, GHQ-30, DBD, SS-A, <i>change in CG situation</i> | Education and support group. |

Table 1: Summary of reviewed papers continued

| Study | Design ¹ | Sample | Burden as primary or secondary outcome | Other caregiver outcomes measured ² | Intervention |
|-------------------------------------|---------------------|--|--|---|--|
| Ostwald <i>et al.</i> , 1999, USA | RCT | N = 117 (mean age 65.6) 65% female | Not reported | CES-D, RMBPC | Education and skills training group. |
| Hébert <i>et al.</i> , 2003, Canada | RCT | N = 144 (mean age 60.0) 61% spousal caregivers 80% female | Secondary | RMPBC, STAI, BRAS, ISSB, PSI, <i>Personal efficacy, Desire to institutionalise</i> | Skills training group. |
| Hepburn <i>et al.</i> , 2003, USA | BA | N = 140 40% spousal caregivers | Not reported | RMPBC, CES-D, Mastery Scale, BACS | Education and skills training group. |
| Hepburn <i>et al.</i> , 2005, USA | RCT | N = 215 (mean age 66.5) 61-68% spousal caregivers across 3 groups (two intervention groups and a waiting list control group) 71-77% female across 3 groups | Not reported | RMPBC, Mastery Scale, CES-D, STAI, BACS, BRAS | Education and skills training group. |
| Winter & Gitlin, 2007, USA | RCT | N = 103 (mean age 66.6, SD=9.1) 57.7% spousal caregivers 100% female | Primary | CES-D, GTGIS | Telephone support group. |
| Dang <i>et al.</i> , 2008, USA | BA | N = 113 (mean age 67.0, SD=14) 66% spousal caregivers 88% female | Primary | CES-D, COPE, SF-36, <i>knowledge about dementia and resources, program satisfaction</i> | Telephone based education, and care co-ordination. |

Table 1: Summary of reviewed papers continued

| Study | Design ¹ | Sample | Burden as primary or secondary outcome | Other caregiver outcomes measured ² | Intervention |
|---|---------------------|---|--|--|--|
| Tremont <i>et al.</i> , 2008, USA | RCT | N = 60 (mean age 63.3) 61% spousal caregivers | Primary | RMPBC, GDS, ADKT, SF-36, SES, FAD, MSPSS | Telephone based education and support. |
| Martin-Carrasco <i>et al.</i> , 2009, Spain | RCT | N = 115 (mean age 58.4) 54.8% spousal caregivers 68.7% female | Primary | SF-36, GHQ-28, <i>use of health & social care resource</i> | Education and skills training group. |
| Lam <i>et al.</i> , 2010, Hong Kong | RCT | N = 102 | Primary | GHQ, PWI-A, <i>use of social care resource</i> | Education and case management. |

¹ Abbreviations: BA = uncontrolled before and after comparison, NRCT = non randomized controlled trial, RCT = randomized controlled trial

² Italics indicate a non-standardised measure. Abbreviations: ZSDS = Zung Self-Rating Depression Scale, MPBC = Memory and Problem Behaviour Checklist, MHI = Mental Health Index, PSSCSC = Perceived Social Support for Caregiving and Social Conflict, GHQ = General Health Questionnaire-30, SWLS = Satisfaction With Life Scale, PANAS = Positive And Negative Affect Scale, BSI = Brief Symptoms Inventory, ADKT = Alzheimer's Disease Knowledge Test, RMPBC = Revised Memory and Problem Behaviour Checklist, HSC = Hopkins Symptom Checklist, ATQ = Automatic Thoughts Questionnaire, JCS = Jalowiec Coping Scale, RAI = Rathus Assertion Inventory, DAS = Dyadic Adjustment Scale, SEIQoL-DW = Schedule for the Evaluation of Individual Quality of Life-Direct Weighting, DBD = Dementia Behaviour Disturbance Scale, SS-A = Vaux Social Support Appraisal Scale, CES-D = Centre for Epidemiological Studies-Depression, STAI = Spielberger State-Trait Anxiety Inventory, BRAS = Bradburn Revised Affect Scale, ISSB = Inventory of Socially Supportive Behaviours, PSI = Psychiatric Symptoms Index, BACS=Beliefs About Caregiving Scale, GTGIS = Gain Through Group Involvement Scale, COPE = Cope Inventory, SF-36 = Short Form Health Survey-36, GDS = Geriatric Depression Scale, SES = Self Efficacy Scale, FAD = Family Assessment Device, MSPSS = Multidimensional Scale of Perceived Social Support, GHQ-28 = General Health Questionnaire-28, GHQ = General Health Questionnaire, PWI-A = Personal Wellbeing Index for Adults.

1.4.2 Methodological quality

The quality criteria used to assess the studies included in this review and their ratings are shown in Table 2. A quality percentage is given for each study, which provides an indication of the relative methodological strength of each study. This suggests that Hébert *et al.* (1994), Hébert *et al.* (2003) and Lam *et al.* (2010) conducted the methodologically strongest studies, all achieving a quality percentage of over 50 per cent. The majority of studies included in this review were of relatively poor methodological quality; they did not report whether and how the allocation of participants to groups was concealed, or whether or how the outcome assessors were blinded to intervention condition, potentially introducing selection and detection biases. Attrition across the included studies was high, with eight studies reporting more than 20 per cent attrition (Dang *et al.*, 2008; Goodman, 1990; Hébert *et al.*, 1994; Hepburn *et al.*, 2003; Hepburn *et al.*, 2005; Martin-Carrasco *et al.*, 2009; Ostwald *et al.*, 1999). Power analyses were reported in only five papers (Hébert *et al.*, 1994; Hébert *et al.*, 2003; Lam *et al.*, 2010; Martin-Carrasco *et al.*, 2009; Winter & Gitlin, 2007) and only one of these studies achieved sufficient power (Winter & Gitlin, 2007). Of the 15 studies included in this review, five reported a significant reduction in caregiver burden post-intervention as measured by the ZBI (Hepburn *et al.*, 2003; Kahan *et al.*, 1985; Martin-Carrasco *et al.*, 2009; Ostwald *et al.*, 1999; Tremont *et al.*, 2008), none of which had achieved adequate statistical power. The three studies scoring a minimum of 50 per cent for methodological quality (Hébert *et al.*, 1994; Hébert *et al.*, 2003; Lam *et al.*, 2010) did not find a significant effect of their psychosocial intervention on caregiver burden, as measured by the ZBI.

Table 2: Evaluation of methodological quality

| Study | Study design | Randomisation | Allocation | Blinding | Confounds controlled | Equal drop out | Total drop out 20% | Intention to treat analysis. | Power analysis | Power achieved | Score (%) |
|------------------------------|--------------|----------------------|---------------|----------------------|----------------------|----------------|--------------------|------------------------------|----------------|----------------|------------|
| Kahan <i>et al.</i> , 1985 | BA | N/A | Not addressed | Not addressed | Adequately addressed | No | No | N/A | No | Not reported | 1/10 (10%) |
| Goodman 1990 | RCT | Adequately addressed | Not addressed | Not addressed | Adequately addressed | No | No | Not addressed | No | Not reported | 2/14 (14%) |
| Brodaty <i>et al.</i> , 1994 | NRCT | N/A | Not addressed | Not addressed | Well covered | No | Yes | N/A | Yes | No | 4/10 (40%) |
| Hébert <i>et al.</i> , 1994 | RCT | Adequately addressed | Not addressed | Adequately addressed | Well covered | No | No | Well covered | Yes | No | 7/14 (50%) |
| Gendron <i>et al.</i> , 1996 | RCT | Adequately addressed | Not addressed | Adequately addressed | Well covered | No | No | Not addressed | No | Not reported | 4/14 (29%) |
| Coen <i>et al.</i> , 1999 | BA | N/A | N/A | N/A | N/A | N/A | Yes | N/A | No | Not reported | 1/3 (33%) |
| Ostwald <i>et al.</i> , 1999 | RCT | Well covered | Not addressed | Not addressed | Adequately addressed | No | Yes | Not addressed | No | Not reported | 4/14 (29%) |
| Hébert <i>et al.</i> , 2003 | RCT | Well covered | Not addressed | Adequately addressed | Well covered | No | Yes | Well covered | Yes | No | 9/14 (64%) |

Table 2: Evaluation of methodological quality continued

| Study | Study design | Randomisation | Allocation | Blinding | Confounds controlled | Equal drop out | Total drop out 20% | Intention to treat analysis. | Power analysis | Power achieved | Score (%) |
|--------------------------------------|--------------|----------------------|----------------------|----------------------|----------------------|----------------|--------------------|------------------------------|----------------|----------------|-------------|
| Hepburn <i>et al.</i> , 2003 | BA | N/A | N/A | N/A | N/A | N/A | No | N/A | No | Not reported | 0/3 (0%) |
| Hepburn <i>et al.</i> , 2005 | RCT | Well covered | Not addressed | Not addressed | Well covered | No | No | Not addressed | No | Not reported | 4/14 (29%) |
| Winter & Gitlin, 2007 | RCT | Adequately addressed | Not addressed | Not addressed | Poorly addressed | Not reported | Yes | Not addressed | Yes | Yes | 4/14 (29%) |
| Dang <i>et al.</i> , 2008 | BA | N/A | N/A | N/A | N/A | N/A | No | N/A | No | Not reported | 0/3 (0%) |
| Tremont <i>et al.</i> , 2008 | RCT | Well covered | Not addressed | Adequately addressed | Well covered | No | No | Poorly addressed | No | Not reported | 5/14 (36%) |
| Martin-Carrasco <i>et al.</i> , 2009 | RCT | Well covered | Not addressed | Not addressed | Well covered | No | No | Not addressed | Yes | No | 5/14 (36%) |
| Lam <i>et al.</i> , 2010 | RCT | Well covered | Adequately addressed | Adequately addressed | Well covered | Yes | Yes | Adequately addressed | Yes | No | 10/14 (71%) |

Full criteria: 1) The assignment of subjects to treatment groups is randomized 2) An adequate concealment method is used 3) Outcome assessors are kept 'blind' about treatment allocation 4) The treatment and control groups are similar at the start of the trial (or any differences are adequately controlled for) 5) Participant drop out is equal across groups 6) Total drop out is less than 20% 7) All participants are analysed in the groups to which they were randomly allocated (intention to treat analysis) 8) Appropriate power analysis is reported 9) Adequate statistic power is achieved.

Criteria 1, 2, 3, 4 and 7 could be rated as well covered (2 points), adequately addressed (1 point), poorly addressed, not addressed, not reported or not applicable (all 0 points). Criteria 5, 6, 8 and 9 could be rated as yes (1 point) or no, not applicable or not reported yields (0 points).

1.4.2 Congruence

The congruence scores between components of the Zarit Burden Inventory (ZBI) and study interventions are shown in Table 3. Overall, congruence was found to be low in all studies, with the exception of Hébert *et al.* (2003) and Tremont *et al.* (2008), which showed moderate congruence between the intervention and the components of the ZBI as assessed by the quality criteria described previously. Congruence was most commonly found between study interventions and the psychological wellbeing component of the ZBI (e.g. Brodaty *et al.*, 1994; Coen *et al.*, 1999; Goodman, 1990; Hébert *et al.*, 2003), and also between study interventions and the social life component of the ZBI (e.g. Brodaty *et al.*, 1994; Goodman, 1990; Hébert *et al.*, 2003; Winter & Gitlin, 2007).

Eight studies (Brodaty *et al.*, 1994; Coen *et al.*, 1999; Goodman, 1990; Hébert *et al.*, 2003; Hepburn *et al.*, 2003; Hepburn *et al.*, 2005; Martin-Carrasco *et al.*, 2009; Tremont *et al.*, 2008) explicitly designed interventions to target caregivers' psychological wellbeing. Brodaty *et al.* (1994), Coen *et al.* (1999), Goodman (1990), Hébert *et al.* (2003) and Martin-Carrasco *et al.* (2009) all reported the aim of increasing psychological wellbeing or life satisfaction, Hepburn *et al.* (2003), Hepburn *et al.* (2005), Martin-Carrasco *et al.* (2009) and Tremont *et al.* (2008) sought a reduction in psychological stress or distress. Five studies (Brodaty *et al.*, 1994; Goodman, 1990; Hébert *et al.*, 2003; Tremont *et al.*, 2008; Winter & Gitlin, 2007) reported explicitly designing the intervention to target the impact of caregiving on the caregivers' social lives; Brodaty *et al.* (1994) sought to increase social satisfaction, Goodman (1990), Winter & Gitlin (2007), Tremont *et al.* (2008) and Hébert *et al.* (2003) aimed to increase perceived social support, with Hébert *et al.* (2003) and Tremont *et al.* (2008) also aiming to improve social support seeking skills. Only one study (Tremont *et al.*, 2008) explicitly targeted the physical health component of the ZBI. By directly assessing physical health issues and recommending and assisting caregivers to access relevant information and resources (including a physician or other physical health services), Tremont *et al.* (2008) anticipated that their intervention may affect caregivers' physical health. The

remaining two ZBI components, relationship between caregiver and care recipient and finances, were not found to have been explicitly targeted by any study included in this current review. No studies reported a theoretical explanation or mechanism by which their intervention might affect these two components of burden.

The quality criteria assessed congruence at two levels: at the level of content (the results of which are reported above) and at the level of theory. Seven studies reported a theoretical mechanism by which the intervention was anticipated to affect the psychological wellbeing component of burden (Gendron, Poitras, Dastoor & Pérodeau, 1996; Hébert *et al.*, 2003; Hepburn *et al.*, 2003; Hepburn *et al.*, 2005; Martin-Carrasco *et al.*, 2009; Tremont *et al.*, 2008; Winter & Gitlin, 2007). The two theories most commonly used as explanatory frameworks were cognitive behavioural theory (Gendron *et al.*, 1996; Hébert *et al.*, 2003; Martin-Carrasco *et al.*, 2009) and stress mediation theory (Hepburn *et al.*, 2003; Hepburn *et al.*, 2005; Tremont *et al.*, 2008; Winter & Gitlin, 2007). For example, the intervention by Martin-Carrasco *et al.* (2009) included teaching caregivers stress and tension control techniques and strategies to manage the care recipient's behavioural problems as well as using cognitive restructuring. According to cognitive behavioural theory (Beck, Rush, Shaw & Emery, 1979), the caregivers should be better able to reduce physical symptoms of anxiety, challenge negative automatic thoughts and care effectively for the care recipient, allowing them to pursue rewarding activities for themselves, all of which should contribute to improved psychological wellbeing. The anticipated effect of the intervention evaluated by Tremont *et al.* (2008) for example, is explained using stress process theory (Lazarus & Folkman, 1984; Pearlin, Mullan, Semple & Skaff, 1990). By providing emotional support, directing caregivers to resources and teaching strategies to manage ongoing difficulties, when a challenging situation arises and the appraisal process begins, caregivers should appraise their abilities and resources as sufficient to meet the challenge, therefore reducing psychological distress.

Four studies described a theoretical mechanism of action through which the intervention should affect the social life component of burden. Stress mediation theory was again referenced here (Hébert *et al.*, 2003; Tremont *et al.*, 2008; Winter & Gitlin, 2007) as well as a social network theory of self-help support groups (Borkman, 1984) cited by Goodman (1990), whereby participation in self-help services increases the caregiver's confidence in their experiential knowledge, supplements other less supportive relationships and facilitates use of other informal social supports over time.

Table 3: Congruence between interventions and ZBI components

| | Psychological wellbeing | | Relationship between caregiver & care recipient | | Physical health | | Finances | | Social Life | | Class |
|------------------------------|-------------------------|------------|---|------------|-----------------|------------|------------|------------|-------------|------------|----------|
| | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | |
| Kahan <i>et al.</i> , 1985 | - | - | - | - | - | - | - | - | - | - | Low |
| Goodman, 1990 | ✓ | - | - | - | - | - | - | - | ✓ | ✓ | Low |
| Brodaty <i>et al.</i> , 1994 | ✓ | - | - | - | - | - | - | - | ✓ | - | Low |
| Hébert <i>et al.</i> , 1994 | - | - | - | - | - | - | - | - | - | - | Low |
| Gendron <i>et al.</i> , 1996 | - | ✓ | - | - | - | - | - | - | - | - | Low |
| Coen <i>et al.</i> , 1999 | ✓ | - | - | - | - | - | - | - | - | - | Low |
| Ostwald <i>et al.</i> , 1999 | - | - | - | - | - | - | - | - | - | - | Low |
| Hébert <i>et al.</i> , 2003 | ✓ | ✓ | - | - | - | - | - | - | ✓ | ✓ | Moderate |

NB: Criteria 1) Intervention specifically designed to affect this component. Criteria 2) Theoretical explanation / mechanism reported.

Table 3: Congruence between interventions and ZBI components continued

| | Psychological wellbeing | | Relationship between caregiver & care recipient | | Physical health | | Finances | | Social Life | | Class |
|--------------------------------------|-------------------------|------------|---|------------|-----------------|------------|------------|------------|-------------|------------|----------|
| | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | Criteria 1 | Criteria 2 | |
| Hepburn <i>et al.</i> , 2003 | ✓ | ✓ | - | - | - | - | - | - | - | - | Low |
| Hepburn <i>et al.</i> , 2005 | ✓ | ✓ | - | - | - | - | - | - | - | - | Low |
| Winter & Gitlin, 2007 | - | ✓ | - | - | - | - | - | - | ✓ | ✓ | Low |
| Dang <i>et al.</i> , 2008 | - | - | - | - | - | - | - | - | - | - | Low |
| Tremont <i>et al.</i> , 2008 | ✓ | ✓ | - | - | ✓ | ✓ | - | - | ✓ | ✓ | Moderate |
| Martin-Carrasco <i>et al.</i> , 2009 | ✓ | ✓ | - | - | - | - | - | - | - | - | Low |
| Lam <i>et al.</i> , 2010 | - | - | - | - | - | - | - | - | - | - | Low |

NB: Criteria 1) Intervention specifically designed to affect this component. Criteria 2) Theoretical explanation / mechanism reported.

1.5 Discussion

1.5.1 Congruence

The results of this systematic review indicate that there is limited congruence between the specified aims of psychosocial interventions evaluated using the ZBI, and the five components of the ZBI itself: caregiver's health, psychological wellbeing, finances, social life and the relationship between the caregiver and care recipient; 13 out of 15 studies received a low congruence classification (see Table 4). As shown in Table 4, eight studies out of the 15 included studies reported explicitly designing the intervention to target caregivers' psychological wellbeing and five studies reported explicitly designing the intervention to target caregivers' social lives. The focus of interventions included in this review was predominantly on the psychological and social aspects of the burden of caring for someone with dementia (with the exception of Tremont *et al.* [2008], who also targeted caregivers' physical health). The other aspects of caregiver burden as conceptualized by Zarit *et al.* (1980), finances or the relationship between the caregiver and care recipient, were not explicitly targeted by any study included in this review.

The lack of congruence between the five components of the ZBI and study interventions found by this review is interesting, as it suggests that the ZBI is unlikely to detect any change post intervention when using the global score, as the content of the intervention at best only partially matches that of the measure. This lack of congruence also has implications for systematic reviews and meta-analyses in this area. The lack of congruence between intervention and burden measure in primary studies means the conclusions of review articles regarding the effectiveness of psychosocial interventions for caregiver burden may be unreliable.

It is possible that burden may not have been the primary outcome for all studies and may have simply been included in a battery of measures in order to have a comprehensive assessment, in which case it may not be expected for the intervention

to explicitly target the components of caregiver burden. Nine studies did not report whether burden was a primary or secondary outcome measure. However, even in the five studies which reported that burden was primary outcome, congruence was still found to be low.

The results of this review not only indicate a lack of correspondence between interventions and the burden outcome measure used, but also highlight the overlap between outcome measures used. All studies except one (Lam *et al.*, 2010) also included measures of depression, affect, general mental health or satisfaction with social support. Given that the principle areas of congruence between intervention design and the ZBI lies in the areas of psychological wellbeing and social life, within these studies the ZBI may not be measuring anything in addition to other outcome measures already included which evaluate psychological distress and social support. This overlap may be a product of the global construct of burden used by the ZBI, which is more likely to overlap with other outcome measures. In such cases, researchers may find it more appropriate to use alternative measures of burden which measure discrete components of burden, or to omit a measure of burden if its constituent parts being targeted are already measured by other scales.

The fact that no study targeted the caregivers' finances or the relationship between the caregiver and care recipient, as measured by the ZBI, raises questions over the conceptualizations of burden used by researchers. The ZBI is consistent with a multidimensional conceptualization of burden; however this conceptualization is not reflected in the design of study interventions. It may be that researchers have simply chosen to focus on psychological and social aspects of caregiver burden. However, this raises the question of why a global measure of caregiver burden was used to evaluate the impact of the intervention on psychological distress and social support when this could be assessed with specific outcome measures instead. No study included in this review referenced a theoretical model of burden in relation to its intervention design or choice of burden outcome measure, even when burden was

identified as a primary outcome, which raises the possibility that this may not have been considered. Given the variety of models of caregiver burden in the literature and the plethora of measurement tools available, which measure different aspects of caregiver burden, providing such a reference enables the reader to draw on the same theory as the study authors and to evaluate the rationale for the intervention more accurately. Reporting such details may not be necessary when the key outcome of a study is well defined and operationalized (e.g. major depressive disorder as defined by DSM-IV [American Psychiatric Association, 2000]), however when the outcome is a relatively poorly defined construct such as caregiver burden, such reporting is more important.

1.5.2 Mechanism of change

Results of this review suggest that there is limited reporting of hypothesized mechanisms of change postulating how the interventions will reduce specific components of caregiver burden. As shown in Table 4, seven out of 15 studies reported a hypothesized mechanism of change for the psychological wellbeing component of the ZBI and four out of 15 studies reported a hypothesized mechanism of change for the social life component of the ZBI. It is possible that mechanisms of change may have been considered but not reported by study authors. However, without a clear description, consideration of hypothesized mechanisms of change cannot be assumed.

Leading researchers (Knight *et al.*, 1993; Zarit & Femia, 2008) have drawn attention to the fact that the mechanism of change in interventions must be specified and tested. Specifying the theoretical model of how the treatment is supposed to work not only helps researchers to consider the likelihood of the treatment having the proposed effect, but if the mechanisms of change are measured, then these mediational relationships can be tested and theoretical knowledge refined. With respect to the psychological wellbeing component of the ZBI, of the seven studies published before 2000, one reported a theoretical mechanism of change for this

component. Of the eight studies published since 2000, six reported a theoretical explanation. This may indicate that progress is being made in this area or it may be an artefact of improvements in reporting quality. However, theoretical mechanisms of change were not commonly reported for other components of burden.

1.5.3 The ZBI

It is important to note that Zarit *et al.* (1980) provide labels but no clear definitions or descriptions of the five components of the ZBI. The lack of clear definition of ZBI components may give rise to conflicting understandings of what is meant by each component and contribute to a discrepancy between the areas targeted by the intervention and ZBI components. It is interesting that early researchers in the field of caregiver burden used the conceptual structure of the ZBI provided by Zarit *et al.* (1980) but did not empirically test the factor structure. Factor analyses have subsequently been completed (Ankri, Andrieu, Beaufils, Grand & Henrard, 2005; Knight, Fox & Chou, 2000; Siegert, Jackson, Tennant & Turner-Stokes, 2010; Whitlach, Zarit & von Eye, 1991). These have produced two and three factor solutions; the two factor solution (Whitlach *et al.*, 1991) comprises a personal strain factor (emotional reactions to caregiving) and a role strain factor (stress due to role conflict or overload). The three factor solutions include a guilt or self-criticism factor in addition to personal strain and role strain factors (Ankri *et al.*, 2005; Knight *et al.*, 2000; Siegert *et al.*, 2010). Not all of the 22 items load sufficiently on these factors, suggesting that some items are redundant in the measurement of these factors. This review did not examine congruence between study interventions and the two and three factor structures of the ZBI as the factor analyses were published substantially later than some of the intervention studies, making it a biased comparison. Contemporary researchers using the ZBI however, may benefit from considering how their interventions are likely to target personal strain, role strain, and guilt/self-criticism, rather than the original five component conceptual structure described by Zarit *et al.* (1980).

1.5.4 Limitations of this review

The studies included in this review were limited to those published in English and only a limited number of electronic databases were searched using a finite number of search terms. These factors may have led to some relevant studies being inadvertently excluded. The review was also limited to studies using the 22 item ZBI; other measures of caregiver burden are used within the literature. However, in an attempt to ensure the results of the review were meaningful and interpretable only studies using the 22 item ZBI were included, as it was the most frequently used measure within included studies in this review.

The review did not restrict the literature search to a specified time period. It is important to acknowledge that the standards of study design and reporting have advanced significantly over the years, and so it is not surprising that older papers did not achieve such a high score on methodological criteria or report mechanisms of change, although some more recent papers also did poorly in these areas. The results are also limited by what is reported within the articles themselves and any protocols which could be supplied by the study authors. It is possible that researchers considered the individual components of the ZBI and mechanisms of change for their intervention, but did not report them. In order to avoid making unfounded interpretations, the reviewers relied upon explicit statements within study reports and other documentation. However, it cannot be assumed that these issues were not considered at all, simply that they were not reported.

Evaluating congruence between psychosocial interventions and outcome measures is not a common topic for review, and subjective judgements are involved in this process as in all systematic reviews. It is interesting to note that whilst the kappa coefficient for inter-rater reliability was excellent for methodological quality criteria, the kappa coefficient was lower for the congruence quality criteria; it was in the 'fair' range. This is likely to be a reflection of the challenges of assessing a less established criterion such as congruence, which is more reliant on the quality of the

description within a published study, rather than the presence or absence of a statistic or statement of a procedure. Although clear protocols and descriptors were developed to minimize the risk of idiosyncratic judgements, the lower kappa value indicates that there was greater variability in the evaluation of congruence, which limits the strength of the conclusions of this review.

1.5.5 Clinical implications

Results of this review indicate that the current research literature may not provide a reliable answer as to whether psychosocial interventions are effective for burden. In part, this may be due to the lack of congruence between intervention design and the content of the ZBI, and partly because of small and self-selected samples, inadequate statistical power, relatively short follow-up periods and a lack of targeting of interventions to those participants who are most in need of or likely to benefit from the intervention.

If caregiver burden is an outcome targeted by a health or social care service, the content validity of the intervention and the instrument used to measure its effects should be carefully considered. For example, if a service is being provided to primarily relieve objective burden (e.g. by offering regular nursing care within the home) a measure focused on objective burden should be chosen, rather than one which integrates caregiver appraisal or subjective burden. Individual clinicians seeking to monitor a caregiver's progress may find that change is detected more reliably on proximal outcome measures (e.g. knowledge of behavioural management techniques, or self-efficacy for using behavioural management techniques) rather than a distal measure such as burden. It has also been suggested that whilst caregiver burden may be relatively insensitive to change, caregivers may see improvements in their quality of life, and so inclusion of more positive outcome measures may be useful for clinicians (Acton & Kang, 2001).

1.5.6 Research implications

The results of this review indicate that there is limited congruence found between psychosocial interventions and components of the ZBI, and a lack of reporting of theoretical mechanisms of change. Future research studies should carefully consider the hypothesized mechanism by which their intervention will affect caregiver burden. If the intervention is unlikely to directly affect burden, it may be more appropriate to measure the mediating variables rather than burden itself. If burden is included as a key outcome, researchers should be clear about which conceptualisation of caregiver burden they are using and choose a measure which corresponds to this. The hypothesized mechanism of action of the intervention on caregiver burden should be theoretically driven, clearly specified and if possible, tested.

1.5.7 Conclusions

The aim of this review was to evaluate the congruence between individual components of the ZBI and psychosocial interventions evaluated using this scale. Congruence was most commonly found for the psychological wellbeing and social life components of the ZBI, although in a minority of studies. This suggests that the ZBI is less likely to be sensitive to change post-intervention in these studies, if there is no initial match between the content of the scale and the aims of the intervention. It is important to note that all studies included other outcome measures, which may or may not have shown significant change following intervention; this was not considered within this review. To the reviewers' knowledge, at least seven of these studies have been cited in systematic reviews and meta-analyses examining the effectiveness of psychosocial interventions on caregiver burden. There is the risk the results of these systematic reviews and meta-analyses are skewed by studies where there was little correspondence between the intervention and components of the burden outcome measure chosen in the first place. This raises the possibility that interventions are not being offered to caregivers as they have been discarded as ineffective, when they may be effective but not evaluated with appropriate measures.

Future research would benefit from careful consideration of the hypothesized mechanism of action of the chosen intervention, and which outcomes are likely to be sensitive to change. If caregiver burden is thought to be one such outcome, researchers should clearly state what they mean by burden, and review the content of burden measures in order to choose one that fits with the theoretical underpinnings of the intervention and study.

1.5.8 Key practitioner messages:

- The majority of psychosocial intervention studies targeting dementia caregiver burden showed low congruence with the five components of burden measured by the ZBI, which was used to evaluate the interventions.
- There is limited reporting of the theoretical mechanisms of action by which psychosocial interventions are hypothesised to affect caregiver burden.
- As there is not a universally accepted definition of caregiver burden, clinicians and researchers should clearly specify the definition of caregiver burden that they are using and choose a measure of caregiver burden which corresponds to this.
- The theoretical mechanism of action of the intervention on caregiver burden should be specified and where possible, tested.

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2 Thesis Aims and Hypotheses

Leading researchers (Brodaty, 2007; Knight *et al.*, 1993; Zarit & Femia, 2008) have called for more sophisticated research designs in caregiver intervention research; by using theoretically grounded interventions, considering the likely mechanisms of action and using appropriate outcome measures. The preceding systematic review illustrated that in studies using the Zarit Burden Interview (ZBI: Zarit *et al.*, 1980), these issues are frequently inadequately considered.

2.1 Choice of outcome measures

Zarit and Femia (2008) highlight that caregiving is commonly treated as a disorder as though all caregivers are depressed; however, 50 – 80 per cent of caregivers do not suffer from significant depressive symptomatology. A measure of depression is therefore not always an appropriate outcome measure due to floor effects. Guilt has been shown to be associated with depression in the general population (Kim *et al.*, 2011) and a common experience of caregivers (Rosa *et al.*, 2010; Samuelsson *et al.*, 2001). Gonyea *et al.* (2008) found that 65% of their sample of adult-child caregivers experienced guilt in relation to their caregiving role. Although guilt is a common experience of caregivers, without a psychometrically robust measure with a clinical cut off, it is difficult to measure and ascertain what level of guilt is likely to be dysfunctional.

Martin *et al.* (2006) designed a caregiving shame and guilt scale, with six items pertaining to caregiver guilt, although subscales were not identified through factor analysis. In a sample of 70 dementia caregivers, Martin *et al.* (2006) found guilt was not associated with depression in caregivers, a surprising finding given that guilt is associated with depression in the general population (Kim *et al.*, 2011). However this finding may be confounded by correlating current depressive symptomatology,

(measured by the Centre for Epidemiological Studies Depression Scale [CES-D:Radloff, 1977]), with the conditional phrasing of most of the guilt items. Statements were worded in terms of how the caregivers would feel *if* they acted in a certain manner in relation to caregiving behaviours e.g. “I would worry about my relative if I did not care for them as I do”. An alternative guilt scale was identified by Ankri *et al.* (2005), in a factor analysis of the ZBI (Zarit *et al.*, 1980). A four item guilt factor was identified, which was found to be associated with depression. Given that current models of guilt (e.g. Tangney & Dearing, 2002) suggest that the object of negative evaluation in guilt is a specific behaviour, it is likely that a four item (Ankri *et al.*, 2005) or six item (Martin *et al.*, 2006) scale will not measure all relevant caregiving behaviours which may relate to caregiver guilt. In addition, neither scale yields a clinical cut off that indicates a level of guilt which is likely to be dysfunctional.

The Caregiver Guilt Questionnaire (CGQ: Losada *et al.*, 2010), a 22 item self-report measure, was developed to address the shortcomings of existing measures. A large number of items were tested and reduced using factor analysis, in order to develop a measure of caregiver guilt which encompasses a wide range of caregiving behaviours relevant to the experience of guilt in a psychometrically robust manner. In a sample of 288 Spanish dementia caregivers, a principal components analysis identified a five factor structure, which explained 59.3 per cent of the variance. Convergent validity was established with the ZBI guilt factor and internal consistencies for the whole scale and five subscales were found to be adequate to good (Cronbach's α 0.61 – 0.89). Although the CGQ was found to be associated with depression, in the absence of a cut off it is difficult to ascertain what level of guilt is likely to be clinically significant. While the CGQ was published in English, its psychometric properties have not been evaluated with an English-speaking population. The aim of this study is to test the psychometric properties of the CGQ in a sample of British dementia caregivers and to establish a clinical cut off.

2.2 Mechanism of change

Zarit and Femia (2008) emphasise the importance of empirical evidence to support a hypothesised mechanism of change within an intervention; a recent systematic review indicated that this is not commonly considered (Pinquart & Sorensen, 2006). Caregiver interventions based on cognitive behavioural therapy (CBT) have been shown to be effective in reducing emotional distress in dementia caregivers (Gallagher-Thompson & Coon, 2007; Pinquart & Sorensen, 2006; Sorensen *et al.*, 2002). CBT interventions have aimed to help caregivers to appraise care-recipient's behaviour more realistically and to promote more adaptive behaviours, such as assertive communication, relaxation and an increase in pleasant activities (Gallagher-Thompson *et al.*, 2003). These interventions use a range of techniques, described by Beck (1979), to reduce negative thoughts and attitudes and increase the reinforcement of more adaptive behaviours. However these hypothesised mechanisms of change have not been empirically tested.

Out with the caregiving literature, some component analyses have been conducted to investigate the hypothesised mechanisms of action within CBT. Jacobson *et al.* (1996) compared CBT (including behavioural activation, challenging automatic thoughts and modification of underlying cognitive schema) with a behavioural activation condition and an automatic thought condition (which included behavioural activation as well as modification of negative automatic thoughts) in a sample of 152 depressed patients. No significant differences were found between the three conditions at the end of treatment or at six month follow up. Although there were limitations to this study, such as a broad definition of treatment conditions and the potential confounding between behavioural and cognitive components, the authors concluded that these findings cast some doubt over the hypothesised mechanisms of change within CBT proposed by Beck (1993). This study was later replicated in a larger sample (n=241) (Dimidjian *et al.*, 2006), in which full CBT was found to be no more effective than the behavioural activation condition.

Jacobsen *et al.* (1996) also used the Automatic Thoughts Questionnaire (ATQ: Hollon & Kendall, 1980) to test whether a reduction in depression was mediated by changes in cognitive content, however no significant relationship was found. Contradictory findings have been reported elsewhere; DeRubeis *et al.* (1990) compared measures of cognitive content in two treatment conditions for major depressive disorder, cognitive therapy and medication. Cognitive content at mid-treatment predicted changes in depression scores between mid-treatment and post-treatment in the cognitive therapy condition, but not in the medication condition.

In a review of 13 CBT component studies, Longmore and Worrell (2007) conclude that there is a lack of empirical support for the central assumption within CBT that the content of thought must be challenged or modified in order to reduce emotional distress. Hofmann (2008) disputes these conclusions, arguing that statistical tests for appropriate mediational analysis have only recently become available. He also contends that cognitive change can be achieved by other means than direct challenge or modification, for example a behavioural intervention such as exposure may lead to cognitive changes (e.g. in fear expectancy). The debate regarding mechanisms of change within CBT is ongoing; however, there have been no empirical studies of this within the caregiving literature, despite calls for more sophisticated research designs (Brodaty, 2007; Knight *et al.*, 1993; Zarit & Femia, 2008). In order for cognitive content to be tested as a mediator of changes within CBT interventions for dementia caregivers, appropriate measures are essential.

Although generic measures of dysfunctional thoughts and attitudes exist within the literature (e.g. Hollon & Kendall, 1980; Weissman & Beck, 1978), a caregiving specific measure has only recently been developed (Montorio *et al.*, 2009). The Dysfunctional Thoughts About Caregiving Questionnaire (DTACQ) was developed with a sample of 227 Spanish dementia caregivers, but the reliability and validity of this measure has not yet been established in an English-speaking population. This

study aims to investigate the psychometric properties of the DTACQ in a sample of British dementia caregivers.

2.3 New psychotherapeutic approaches to emotional distress in dementia caregivers

CBT for emotional distress in dementia caregivers has the largest effect sizes amongst psychotherapeutic interventions (Pinquart & Sorensen, 2006); however, interest is growing in alternative psychotherapeutic approaches, including contextual behavioural therapies. One such approach, Acceptance and Commitment Therapy (ACT), has recently been considered for use with this population. Preliminary studies, testing the suitability of this approach for dementia caregivers suffering from depression, have been published (Márquez-González *et al.*, 2010; Spira *et al.*, 2007).

The ACT model of psychopathology states that emotional distress arises from ‘psychological inflexibility’, which can be defined as ‘the way that language and cognition interact with direct contingencies to produce an inability to persist or change behaviour in the service of long-term valued ends’ (Hayes *et al.*, 2006, p. 6). Psychological inflexibility is composed of six overlapping and interdependent processes, as illustrated in Figure 2.

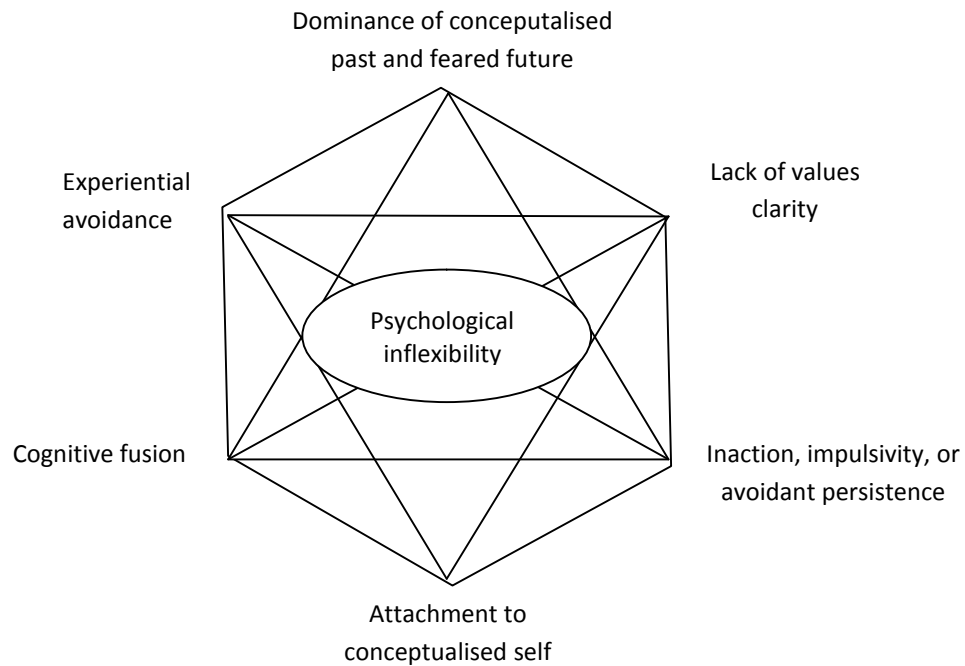


Figure 2: ACT model of psychological inflexibility

Experiential avoidance is described as an unwillingness to be in contact with internal private events and the steps that are taken to alter the form or frequency of these events, potentially with maladaptive behaviours (Hayes *et al.*, 2003). Cognitive fusion is defined as the 'excessive or improper regulation of behaviour by verbal processes, such as rules and derived relational networks' (Hayes *et al.*, 2006, p. 6) or more simply, the process of taking thoughts literally and being entangled with them. Attachment to the conceptualised self and dominance of the conceptualised past and future are similar to cognitive fusion, in that they refer to fusion with verbally based conceptualisations of the past, future and self. Lack of values clarity and inactivity and impulsivity refer to more overt behaviours, whereby a person is unaware of or not connected with their personal values, and where they are not taking any action or effective action towards these values.

ACT seeks to improve psychological flexibility, the ability to be in contact with the present moment and current experience and to change or continue with behaviour in order to pursue one's valued directions, with six core processes that are in essence the opposite of those shown in Figure 2 (see Figure 3).

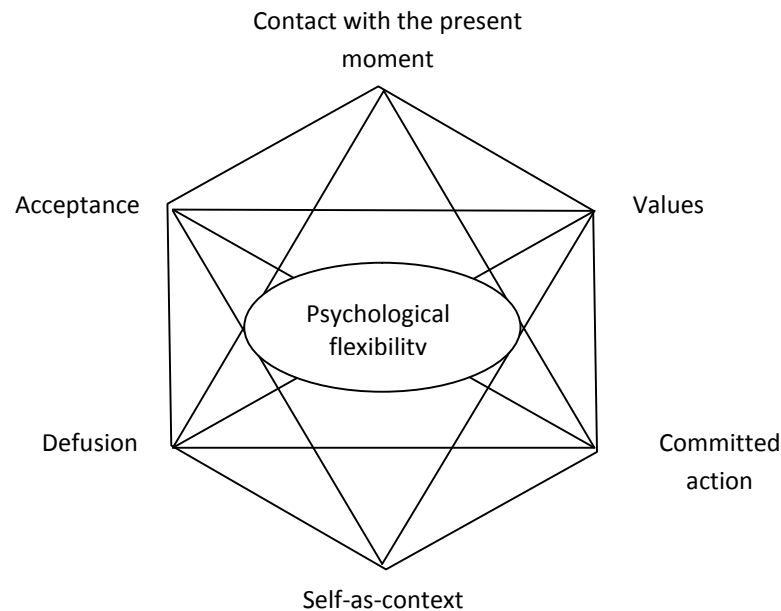


Figure 3: ACT model of psychological flexibility

There has been extensive discussion in the literature regarding similarities and differences between CBT and ACT (e.g. Arch & Craske, 2008; Hayes, 2008; Hofmann & Asmundson, 2008). Both draw on behavioural psychological models and the assumption that behavioural and emotional change can be achieved by altering learned associations. A CBT model of psychopathology assumes that exaggerated or biased forms of thinking contribute to the development and maintenance of a patient's difficulties therefore the recognition, challenging and modification of the form and frequency of these dysfunctional thoughts is required to reduce psychopathology (Clark, 1995). Although ACT is conceptualised as being part of a broad cognitive behavioural tradition (Hayes, 2008), it considers thinking to be another form of behaviour and emphasises the importance of the context in which one behaviour (e.g. thinking) influences other (overt) behaviours. ACT is based on

Relational Frame Theory (Hayes *et al.*, 2001), which provides an account of rule governed behaviour. In therapy, ACT creates a context that weakens unhelpful rule governed behaviour, emphasising direct experience rather than verbal beliefs or rules (i.e. shaping direct contingencies) (Hayes *et al.*, 2006).

The most important difference between CBT and ACT in relation to this empirical project is the difference in approach to thoughts. In CBT, the content of thoughts is monitored, tested and modified. Scales relevant to a CBT approach to thoughts are those which focus on the content or form of dysfunctional thoughts or beliefs (e.g. Automatic Thought Questionnaire, Hollon & Kendall, 1980; Dysfunctional Attitudes Scale, Weissman & Beck, 1978). In therapy, the therapist and client engage in discussions and evaluations of the content of dysfunctional thoughts to facilitate a change in the patient's thinking style, in order to change their behaviour. A dementia caregiver may have the belief that "I must always do the right thing or I am a failure as a carer" and have the thought "I'm a terrible carer" when their wife is agitated or distressed. The caregiver may avoid his wife when she is upset so that he does not do the wrong thing. In CBT, evidence would be gathered for and against this thought and belief, an all or nothing thinking and perfectionism bias would be identified and a more balanced thought would be developed, for example "Sometimes I get it right and sometimes I get it wrong, but I do the best I can in looking after my wife", in order to facilitate behavioural change.

In ACT, there is no attempt to change the content of a thought however the way in which the patient relates to that thought is noted – i.e. whether or not the patient becomes entangled with this thought and whether they respond as if the thought is the literal truth. This is referred to as the extent to which a patient is 'fused' or 'defused' with their thoughts. Scales relevant to an ACT approach to thoughts are those which focus on the way in which someone relates to their thoughts (e.g. Cognitive Fusion Questionnaire, Gillanders *et al.*, 2013). In therapy, mindfulness and defusion techniques are employed to enable the client to distance themselves

from their thoughts without any attempt to change the content, form or frequency of that thinking. These techniques aim to enable the patient to refer to their direct experience and to act in accordance with their values, irrespective of the presence of distressing thoughts. In the example given above, the thought that “I’m a terrible carer, I always do the wrong thing for my wife” would be noticed, a non-judgemental attitude towards it would be encouraged and exercises used to facilitate a more defused or ‘stepped back’ relationship to the thought. The patient would be encouraged to identify their core values (e.g. being a loving husband) and in the presence of the thought, connect with and act in accordance with their values, for example by being with their wife in her distressed state.

The model has not been extensively tested in caregiving samples. Spira *et al.* (2007) investigated the relationship between experiential avoidance, as measured by the Acceptance and Action Questionnaire (Hayes *et al.*, 2004) and depression, as measured by the Centre for Epidemiologic Studies Depression Scale (CES-D) in a sample of 28 female dementia caregivers. Experiential avoidance correlated significantly with depression. The small sample size and correlational nature of the study limit the conclusions that can be drawn, however as a preliminary study, it suggests that the ACT model warrants further investigation in this population.

Cognitive fusion has been investigated less than experiential avoidance within the ACT literature. Several studies show cognitive defusion is associated with greater pain tolerance in experimental studies (Gutierrez *et al.*, 2004; Hayes *et al.*, 1999; Takahashi *et al.*, 2002). Within clinical populations, cognitive fusion has been tested as a mediator of change within ACT interventions. Zettle *et al.* (2011) reported a reanalysis of data from an earlier study, comparing ACT group treatment with cognitive therapy group treatment in 25 depressed female participants. Participants in the ACT group showed a significantly greater reduction in depressive symptoms over time than participants in the cognitive therapy group. Levels of cognitive defusion at post-treatment mediated this effect at follow up. The frequency of

negative automatic thoughts and the strength of dysfunctional attitudes did not act as mediators. Gaudiano *et al.* (2010) compared individual ACT (mean sessions = 3) with treatment as usual in 40 inpatients with psychosis. The ACT group showed a significantly greater improvement in hallucination distress at post-treatment and hallucination believability was a significant mediator between treatment condition and hallucination distress at post-treatment. Hallucination frequency did not act as a significant mediator. However, it is important to note several limitations in these studies. The temporality of the relationships has not been fully established as the mediator was measured at the same time as the outcome effects were being observed; both studies had small sample sizes; and the control condition was treatment as usual, which is a broad treatment lacking clear definition.

Although interest is growing in the use of ACT with dementia caregivers, within the caregiving literature the association of cognitive fusion and depression has not been tested. This study aims to examine how the content of cognition (thoughts, beliefs and attitudes) compares to the way in which one relates to those cognitions (entangled versus defused), in their capacity to predict distress in dementia caregivers.

2.4 Hypotheses

This thesis comprises a three part study aimed at contributing to the literature concerning outcome measures for interventions targeting dementia caregivers and the development of the ACT model with new populations. All three parts use data from a cross-sectional quantitative survey of dementia caregivers. Part 1 concerns the psychometric properties of the Caregiver Guilt Questionnaire, Part 2 focuses on the psychometric properties of the Dysfunctional Thoughts About Caregiving Questionnaire and Part 3 concerns the relationships between depression in dementia caregivers and the content of cognition and the relationship one has to cognition.

2.4.1 Part 1

Research Question 1: What are the psychometric properties of the Caregiver Guilt Questionnaire in a British sample of dementia caregivers? The following psychometric properties will be considered: factor structure; internal consistency; clinical cut off; convergent validity with the Zarit Burden Interview guilt factor and the Center for Epidemiological Studies Depression Scale. Normative data will also be reported for demographic groups.

2.4.2 Part 2

Research Question 2: What are the psychometric properties of the Dysfunctional Thoughts About Caregiving Questionnaire in a British sample of dementia caregivers? The following psychometric properties will be considered: factor structure; internal consistency; convergent validity with the Dysfunctional Attitudes Scale and Center for Epidemiological Studies Depression Scale; construct validity with the amount of help received; a clinical cut-off. Normative data will also be reported for demographic groups.

2.4.3 Part 3

Research Question 3: Are caregiver guilt, dysfunctional thoughts about caregiving and cognitive fusion significant predictors of caregiver depression?

Hypothesis 1: Caregiver guilt will be a significant predictor of variance in depression in dementia caregivers.

Hypothesis 2: Cognitive behavioural theory suggests that the distortions and biases in the content of thoughts (as measured by the Dysfunctional Thoughts About

Caregiving Questionnaire) will be a significant predictor of variance in depression in dementia caregivers.

Hypothesis 3: ACT theory suggests that cognitive fusion (as measured by the Cognitive Fusion Questionnaire) will be a significant predictor of variance in depression in dementia caregivers, and will account for more variance than cognitive content (as measured by the Dysfunctional Thoughts About Caregiving Questionnaire).

3 Methodology

3.1 Participants

Participants were informal (familial) caregivers of people with dementia. In order to be eligible to take part in the study, potential participants were required to meet the following criteria:

- The potential participant identified themselves as the primary caregiver for someone with dementia.
- The potential participant was an unpaid caregiver.
- The person with dementia, for whom the potential participant cared, lived in the community.
- The potential participant was 18 years old or over.
- English was the first language of the potential participant.

3.2 Procedure

Participants were recruited in three ways:

- through the Scottish Dementia Clinical Research Network's caregiver research register;
- by giving presentations at local Alzheimer Scotland caregiver meetings; and
- by placing an advertisement about the study in a local Carers' Centre Newsletter

3.2.1 Scottish Dementia Clinical Research Network

Permission was sought from the Scottish Dementia Clinical Research Network (SDCRN) to access their register of caregivers of people with dementia, who expressed an interest in participating in research. This project was formally adopted by the SDCRN (see Appendix 4) and the names and addresses of 593 caregivers of people with dementia were provided to the researcher.

The 593 potential participants were sent a questionnaire pack in the post. Each pack contained an information sheet about the project (see Appendix 5), a consent form (see Appendix 6), the questionnaire (described in further detail below) and a Freepost envelope in which to return the questionnaire and consent form. The participants were also able to complete the questionnaire over the telephone with the researcher if they preferred.

Those potential participants who had not responded to the initial mailing (either by returning a completed questionnaire or by contacting the researcher to decline to participate) were then sent a second questionnaire pack three months after the initial mailing. The second pack was identical in content to the first.

3.2.2 Presentations at Alzheimer Scotland Caregiver Meetings

Permission was sought from local Alzheimer Scotland managers to give presentations about the project at caregiver meetings. Presentations were given at four caregiver meetings, explaining the purpose of the project, clarifying what participation would involve and offering the opportunity to ask the researcher questions. Questionnaire packs were distributed to those caregivers who expressed an interest in taking part in the project. Each pack contained an information sheet about the project (see Appendix 7), a consent form (see Appendix 6), the questionnaire (described in further detail below) and a Freepost envelope in which to

return the questionnaire. The participants were also able to complete the questionnaire over the telephone with the researcher if they preferred.

3.2.3 Advertisement in the local Carers' Centre Newsletter

Permission was sought from a local Carers' Centre to place an advertisement in its quarterly newsletter. The advertisement (see Appendix 8) asked potential participants to contact the researcher by telephone or email to request a questionnaire pack, identical to those distributed at Alzheimer Scotland caregiver meetings. The advertisement also gave the hyperlink to the online version of the questionnaire pack, hosted by Bristol Online Surveys. The online version of the questionnaire pack included the same text as the information sheet (see Appendix 7), consent form (see Appendix 6) and questionnaire (described in further detail below).

3.2.4 Data Management

When returned to the researcher, completed questionnaires were separated from completed consent forms to maintain anonymity of the participants. Paper documents were kept within a locked filing cabinet on NHS premises. Anonymous data were entered for analysis using the Statistical Package for the Social Sciences (SPSS) Version 19. In line with ethical recommendations and guidance, the contact details of those participants who had requested a summary of the project's results, and of those participants who had requested that their GPs be informed of their participation in the research project, were shredded and disposed of confidentially as soon as the reports and/or letters to their GPs were sent.

3.3 Measures

The questionnaire included validated self-report measures and questions to determine demographic characteristics of the sample, as described below.

3.3.1 Demographic Characteristics

Questions were included to assess the following demographic characteristics: the age, sex and education level of the caregiver, his/her relationship to the person with dementia and whether they lived together. Questions relating to the age and sex of the person with dementia were also included, as well as the type of dementia that they had. Finally, questions were also included about the length of the caring relationship, the average time spent caring each day and whether the caregiver received help from others.

3.3.2 Depression

Various measures of depression were considered for use in this study, including the Geriatric Depression Scale (Yesavage *et al.*, 1983), the Beck Depression Inventory II (Beck *et al.*, 1996) and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). However, the measure needed to be suitable for completion by both younger and older adults, and appropriate for use with both clinical and non-clinical levels of depressive symptoms. Accordingly, the Centre for Epidemiological Studies – Depression Scale was chosen (Radloff, 1977). This is a widely used self-report measure assessing depressive symptomatology in community samples. The scale contains 20 items and produces a score between 0 and 60, where a higher score indicates higher levels of depressive symptoms. A score of 16 or greater is used as the cut off to indicate high levels of depressive symptoms. In the initial validation study, internal consistency was found to be high (alpha coefficient of at least 0.84 across the four samples), the scale discriminated between clinical and non-clinical samples and showed moderate correlations with other measures of depression, such as the Hamilton Rating Scale for Depression (Hamilton, 1960) and the Bradburn Negative Affect scale (Bradburn, 1969) (Radloff, 1977). Other studies have also reported similar levels of internal consistency (Devins *et al.*, 1988; Knight *et al.*, 1997; Radloff & Teri, 1986) and have replicated the original four factor model (Knight *et al.*, 1997; Radloff & Teri, 1986), across different populations, including

adults, older adults and those with physical health conditions. The CES-D has been shown to be moderately accurate as a screening tool for Major Depressive Disorder in an older adult population (Haringsma *et al.*, 2004).

3.3.3 Dysfunctional Thoughts About Caregiving

The Dysfunctional Thoughts About Caregiving Questionnaire (DTACQ) is a 16 item self-report measure (Montorio *et al.*, 2009). Participants rate to what extent they agree with the statements on a 5 point Likert scale. Each statement is a specific maladaptive idea, such as: “Caregivers should avoid talking about their problems with others because others have their own lives and don’t need to be bothered with more problems” and “It is selfish for a caregiver to dedicate time to himself/herself when a relative is frail/sick and needs care”. In a sample of 227 Spanish dementia caregivers, the DTACQ showed good internal consistency (Cronbach’s $\alpha = 0.89$ for the total scale) and moderate test-retest reliability ($r = 0.06$; $p < 0.01$). Principal components analysis indicated a two factor structure: perception of sole responsibility and perfectionism. The DTACQ correlates in theoretically predicted directions with measures of general dysfunctional attitudes and support seeking (Montorio *et al.*, 2009).

In order to test the convergent validity of the DTACQ within an English speaking population, various measures of general dysfunctional thoughts or attitudes were considered for inclusion, including the Automatic Thoughts Questionnaire (30 items) (Hollon & Kendall, 1980) and the Dysfunctional Attitudes Scale (40 items) (Weissman & Beck, 1978). In order to minimise item burden on participants, the nine item abbreviated version of the Dysfunctional Attitudes Scale (DAS: Andrews *et al.*, 1993) was chosen for inclusion, as it has been shown to have good internal consistency (Cronbach’s $\alpha = 0.86$) and similar test-retest reliability to the original DAS scale (Andrews *et al.*, 1993).

3.3.4 Caregiver Guilt

The Caregiver Guilt Questionnaire (CGQ) is a 22 item self-report measure (Losada *et al.*, 2010). Participants rate how frequently they have experienced specified thoughts or feelings of guilt over the past two weeks. Sample items include “I have felt bad about getting angry with the person I’m caring for” and “I have felt bad for leaving my relative in the care of someone else while I had fun”. In a sample of 288 Spanish dementia caregivers the scale was shown to have good internal consistency (Cronbach’s $\alpha = 0.88$ for the total scale). A principal components analysis indicated a five factor structure: guilt about doing wrong by the care recipient ($\alpha = 0.89$), guilt about failing to meet the challenges of caregiving ($\alpha = 0.76$), guilt about self-care ($\alpha = 0.69$), guilt about neglecting other relatives ($\alpha = 0.86$) and guilt about having negative feelings towards other people ($\alpha = 0.61$). The CGQ correlates positively with measures of depression and anxiety, as theoretically predicted (Losada *et al.*, 2010).

The Caregiver Guilt Questionnaire is one of the first measures of caregiver guilt. Consequently, this limits the choice of measures available for use to establish convergent validity. Martin and colleagues (2006) designed a 12 item questionnaire assessing shame and guilt amongst caregivers. However, little information is provided regarding the scale’s development and a relatively small sample was used ($n = 70$). Notably, four out of the six guilt items are phrased in the conditional tense, which may lead respondents to provide hypothetical answers, rather than ones which reflect their current experience. Alternatively, several factor analyses of the Zarit Burden Interview (Zarit *et al.*, 1980) have identified a factor relating to guilt (Ankri *et al.*, 2005; Knight *et al.*, 2000; Siegert *et al.*, 2010), although there has been some variation in the items allocated to this factor between studies. The four-item guilt factor from the ZBI identified by Ankri and colleagues was chosen for use as a measure of convergent validity in this study, which would also permit comparisons between data obtained from this study and the original development study of the CGQ (Losada *et al.*, 2010).

3.3.5 Cognitive Fusion

Over the last two decades research has increased in the area of contextual cognitive and behavioural therapies. Acceptance and Commitment Therapy (ACT) is one such therapy and studies have recently been published considering its use with dementia caregivers suffering from depression (Márquez-González *et al.*, 2010; Spira *et al.*, 2007). One of the six core processes in the ACT model of psychopathology is cognitive fusion, the process of being entangled with thoughts or cognitions. In order to establish whether a fusion based approach to cognitions (synonymous with ACT) is as strong a predictor of distress as a content based approach to cognitions (synonymous with CBT), a measure of cognitive fusion was included in this study.

The 13 item Cognitive Fusion Questionnaire (CFQ-13) was used to measure cognitive fusion. It is a self-report measure yielding a score between 13 and 91, where a higher score indicates greater cognitive fusion. The CFQ-13 contains items about literality of thoughts, perspective taking on thoughts, entanglement and struggle with thoughts. The CFQ-13 has been shown to have good psychometric properties with both non-clinical ($\alpha = 0.84$) and clinical samples (α from 0.85 to 0.89) and correlates in theoretically predicted directions with related constructs such as experiential avoidance, mindfulness and psychological distress (Gillanders *et al.*, 2013).

3.4 Ethical Considerations

Ethical approval was sought from and granted by the South East Scotland Research Ethics Committee 1 (see Appendix 9). This process highlighted four main issues for ethical consideration.

3.4.1 Informed consent

Individuals were provided with an information sheet about the study. The information sheet was developed using National Research Ethics Committee guidelines to ensure that enough information was provided to guarantee informed consent. This included information about the purpose and process of the research and what their contribution would involve, confidentiality and the researcher's name and contact details if further information was required before or during the study period. Consent was explicitly sought with a separate consent form.

3.4.2 Anonymity of participants

The names and addresses of potential participants provided by the SDCRN, along with any provided by potential participants responding to advertisements about the study, were held separately from questionnaire data. Participants were assigned a participant number and only the researcher had access to the research key, which linked names and addresses to participant numbers. Once the anonymous data were entered into the computer, and the study summary and/or letter to the participant's GP was sent, if requested by the participant, the research key containing participant numbers and participant names and addresses was destroyed.

3.4.3 Security of data

All paper data and the research key were stored securely in a locked filing cabinet on NHS premises. Electronic data were stored securely on NHS computers. Where transfer between computers was necessary (e.g. to take anonymous data to the University of Edinburgh for discussions with academic supervisors), anonymous data were sent between secure nhs.net email addresses or a NHS issued encrypted memory stick was used.

3.4.4 Risks or burdens

Completing questionnaires concerning their thoughts and emotions about caregiving may have been upsetting for some caregivers. The information sheet clearly highlighted the possibility of this and suggested that they did not start, or that they stopped completing the questionnaire, if this was the case. Participants were advised to speak to their GP if they were concerned about their emotional wellbeing after completing the questionnaires, and the details of the 24 hour Alzheimer Scotland dementia helpline were provided on the questionnaires in case the individual wished to speak to someone about a dementia related issue.

3.5 Statistical Power

Numerous rules of thumb exist regarding sample size for exploratory factor analysis. Considering the ratio of subjects (N) to items being analysed (p) Gorsuch (1983) recommends a minimum $N:p$ ratio of 5:1; Everitt (1975) recommends at least 10:1. Recommendations are also made on the basis of absolute sample size; Comrey and Lee (1992) suggest that a sample of 100 cases is poor, 200 is fair, 300 is good and a sample of 500 or more cases is very good. A Monte Carlo study by MacCallum *et al.* (1999) suggested that sample sizes as low as 60 cases can be adequate if the communalities are consistently high (all greater than .6). When communalities are lower, the sample size and overdetermination of factors play a more significant role in the recovery of population factors. With communalities in the .5 range, well determined factors and a larger sample size ($n = 100-200$) are required, in order to achieve a good recovery of population factors.

The two questionnaires to be factor analysed (DTACQ and CGQ) contain 16 and 22 items respectively. Accordingly, this study aimed to recruit a minimum sample of $n=220$; this meets Everitt's (1975) recommendation of a $N:p$ ratio 10:1, is a fair sample size, according to Comrey and Lee's (1992) classification, and allows for adequate recovery of population factors, assuming well determined factors and communalities in the .5 range are achieved (MacCallum *et al.*, 1999).

In order to calculate the required sample size to conduct a multiple regression, the number of predictor variables and effect size must be considered. Assuming a medium effect size ($R^2=.13$) and three predictor variables, Cohen (1992) recommends a sample of $n=76$ at $\alpha=.05$ and Green (1991) $n=107$. A sample of $n=220$ should provide adequate statistical power.

3.6 Analytic plan

Raw data were entered into and analysed using SPSS version 19 and analyses were conducted using a significance level of .05 (Cohen, 1992). The normality of the data distributions for the CES-D, DTCQ, CGQ, CFQ, DAS and ZBI were examined using histograms and z scores for skewness and kurtosis. Homogeneity of variance for the CES-D, DTCQ, CGQ, CFQ, DAS and ZBI data was tested using Levene's test.

The factor structures of the DTCQ and CGQ were examined using an exploratory factor analytic technique, principal axis factoring, as recommended by Russell (2002). To establish the appropriateness of using factor analysis, the Kaiser-Meyer-Olkin (KMO) statistic was used to examine the level of diffusion in the pattern of correlations, and Bartlett's test of sphericity to examine whether there are correlational relationships between the variables included in the analysis. Scree plots, parallel analysis and Velicer's MAP test were used to establish the number of factors identified and Promax oblique rotations were performed, as factors were expected to be interrelated.

Receiver operating characteristic curves were examined to ascertain whether cut off scores on DTACQ and CGQ can be determined to identify participants who show clinical levels of depressive symptoms on the CES-D. Hierarchical multiple

regression was used to establish the amount of variance in CES-D scores predicted by the DTACQ, CGQ and CFQ.

4 Results

4.1 Description of sample

630 questionnaire packs were distributed and 239 packs were returned, giving a response rate of 37.9 per cent. This rate is within the average range for questionnaire based psychological research (Baruch, 1999; Cook *et al.*, 2000). In total, 18 questionnaires were excluded from the study; inclusion criteria were not met for 11 participants and entire scales had been left incomplete by seven participants. It was decided that it would be more robust to exclude these seven sets of data rather than to employ pairwise deletion or impute data for whole scales. Therefore, the final sample was 221 (35.1 per cent response rate). Figure 4 illustrates the recruitment pathway and sources of participants.

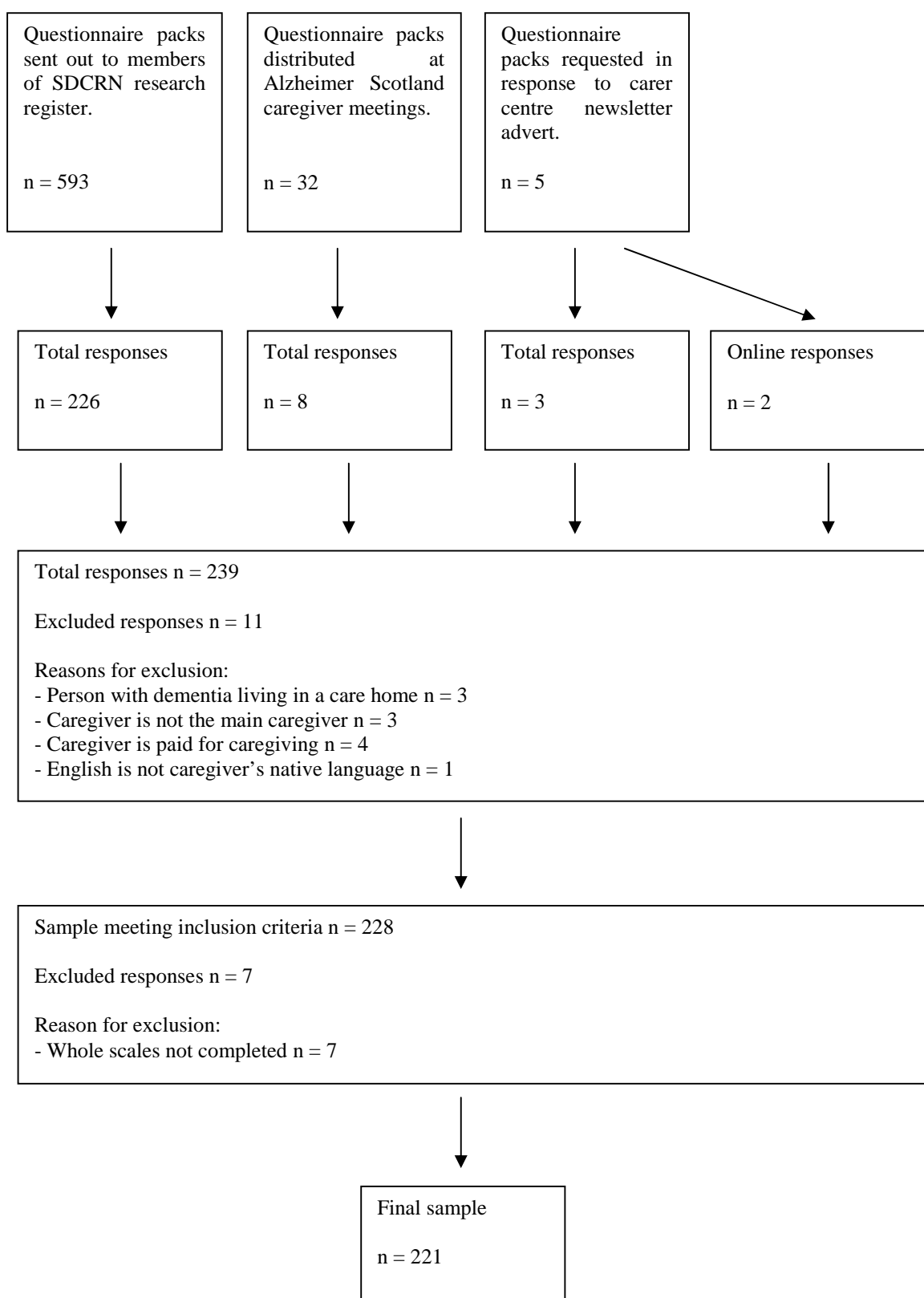


Figure 4: Study recruitment

Overall 65.6 per cent of caregivers were female and 34.4 per cent male. The mean age for caregivers was 68.6 years old (SD: 11.5), with a range from 31 to 95 years. The median age was 70 years. The mean education level for caregivers was 13.4 years (SD: 3.5). The majority of caregivers were spousal caregivers (80.5 per cent), with 17.3 per cent adult-child caregivers. 88 per cent of caregivers lived with the person with dementia. Of the people with dementia who were cared for, 51.8 per cent were male and 48.2 per cent female. The mean age of care recipients was 76 years (SD: 8.2), with a range from 53 to 97 years. In order of frequency, the most common form of dementia was Alzheimer's disease (51.4 per cent), vascular dementia (16.8 per cent), mixed dementia (10.7 per cent), frontotemporal dementia (4.2 per cent) and Lewy body dementia (2.8 per cent). 14 per cent of caregivers did not know what type of dementia the care recipient had.

The mean number of years spent by caregivers caring for the person with dementia was 4.1 years, with a mean number of daily hours caring of 14.6 hours¹. 30.5 per cent of caregivers reported that they received no help with caring for the person with dementia, 49.8 per cent received one source of help, 17.8 per cent received two sources of help and 1.9 per cent received three sources of help. In order of frequency, the most common sources of help were other family members (43.7 per cent), paid carers (33.3 per cent) and then friends (14.1 per cent). The comparison with Losada *et al.*'s (2010) and Montorio *et al.*'s (2009) sample is shown in Table 4.

¹This mean was calculated using all available data. Some caregivers (n=57) reported spending 24 hours caring each day. This was accepted as the subjective experience of caregiving was felt to be most important in this study. If caregivers who reported caring 24 hours each day are removed, the mean daily hours caring becomes 9.6 hours.

Table 4: Sample characteristics for British and Spanish samples

| | | % | <i>M</i> | <i>SD</i> |
|--------------------------------------|------------------------|-------------|----------|-----------|
| Caregiver age (years) | Current study | | 68.6 | 11.5 |
| | Losada <i>et al.</i> | | 59.6 | 12.6 |
| | Montorio <i>et al.</i> | | 58.0 | 14.1 |
| Female caregivers | Current study | 65.6 | | |
| | Losada <i>et al.</i> | 79.2 | | |
| | Montorio <i>et al.</i> | 75.3 | | |
| Years education | Current study | | 13.4 | 3.5 |
| | Losada <i>et al.</i> | | NR | NR |
| | Montorio <i>et al.</i> | | 8.7 | 5.1 |
| Spousal caregivers | Current study | 80.5 | | |
| | Losada <i>et al.</i> | 37.2 | | |
| | Montorio <i>et al.</i> | 44.1 | | |
| Adult-child caregivers | Current study | 17.3 | | |
| | Losada <i>et al.</i> | 57.6 | | |
| | Montorio <i>et al.</i> | 45.8 | | |
| Living with care recipient | Current study | 88.0 | | |
| | Losada <i>et al.</i> | 78.1 | | |
| | Montorio <i>et al.</i> | 71.3 | | |
| Alzheimer's disease : other dementia | Current study | 51.4 : 34.5 | | |
| | Losada <i>et al.</i> | 58.4 : 41.6 | | |
| | Montorio <i>et al.</i> | NR | | |
| Care recipient age (years) | Current study | | 76.0 | 8.2 |
| | Losada <i>et al.</i> | | 79.0 | 8.4 |
| | Montorio <i>et al.</i> | | 76.0 | 8.4 |
| Daily hours caring | Current study | | 14.6 | 8.4 |
| | Losada <i>et al.</i> | | 10.9 | 7.8 |
| | Montorio <i>et al.</i> | | NR | NR |
| Duration of caring (years) | Current study | | 4.1 | 3.5 |
| | Losada <i>et al.</i> | | 4.4 | 3.8 |
| | Montorio <i>et al.</i> | | NR | NR |

NB: NR = not reported.

4.2 Data screening

Raw data were analysed using SPSS version 19 and analyses were conducted using a significance level of .05 (Cohen, 1992). Missing data were examined to see if

patterns could be identified. Little's MCAR test² (Little, 1988) was also used to examine whether data were missing completely at random. This has implications for the method used to impute missing data. The results indicated that data were likely to be missing completely at random for the CES-D, DTACQ, ZBI, DAS and CFQ, however not for the CGQ. Closer inspection of the raw data suggested that there was a pattern of missing data in the CGQ, with items 7, 15 and 16 having the highest levels of incomplete data. These items all refer to the guilt the caregiver experiences when going out without the care recipient. This indicates that these data are missing not at random.

Some simplistic methods of handling missing data (such as listwise deletion, mean or regression substitution) can lead to further problems such as loss of statistical power or underestimation of error variance (Hawthorne & Elliott, 2005; Howell, 2007; Myers, 2011), particularly when data is not missing at random. Expectation maximisation³ (Howell, 2007) was used to impute missing data as it avoids the difficulties associated with simplistic methods described above and is suitable for datasets irrespective of the pattern of missing data.

Histograms and z scores for skewness and kurtosis were used to examine the normality of the data distributions for the CES-D, DTACQ, CGQ, CFQ, DAS and ZBI. It is suggested that in large samples ($n = 200$) visual inspection of the histogram is more important than a z score that is greater than 2.58, due to potential spurious significance results from small standard errors (Field, 2009). Z scores and histograms indicated that the kurtosis of all variables fell within acceptable limits. Z scores and histograms indicated that the skewness of the CES-D, DTACQ, ZBI and

² Little's MCAR test is a chi square statistic, which compares observed and expected means for the missing data group and the complete data group. A significant result indicates that data are not missing completely at random.

³ Expectation maximisation is an iterative process that estimates the missing data based on the observed data and initial estimates of the model parameters, incorporates these data and then re-estimates the model parameters, continuing until stable estimates are reached.

CFQ fell within acceptable limits. The z scores for both the CGQ and DAS indicated significant skewness, however upon examination of the histograms it was thought that the data were distributed normally (see Appendix 10).

The sample size met both Everitt's (1975) criterion for a minimum $N:p$ ratio of 10:1 and Comrey and Lee's (1992) criterion for a 'fair' sample size ($n=200$) (see section 3.5). The CGQ also met MacCallum *et al.*'s (1999) criterion for an adequate sample size of $n=100-200$ when the majority of communalities are above .5; 77.3 per cent were above this level. Only 37.5 per cent of communalities were above .5 for the DTACQ, which indicates that well determined factors and a large sample size are required in order to adequately recover population factors for this measure.

The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy, which assesses the ratio of squared correlation between variables to the squared partial correlation between variables, was well above the accepted level of .5 for both the CGQ (.89) and the DTACQ (.87). This indicates a relatively compact pattern of correlations, which is suitable for factor analysis (Field, 2009). Bartlett's test of sphericity, which assesses whether the correlation matrix is significantly different from an identity matrix (where every variable correlates poorly with every other variable), was significant for both the CGQ and the DTACQ ($p < .001$). This indicates that the variables correlate with each other sufficiently for a factor analysis to be appropriate. Multicollinearity was assessed by examining the variance inflation factor (VIF) and tolerance statistics for the CGQ and DTACQ, which are calculated by regressing each item in the scale onto every other item in the scale. The VIF and tolerance statistics for all items on the CGQ and DTACQ were within acceptable limits ($VIF < 10$ and $\text{tolerance} > 0.1$) (Field, 2009) indicating that multicollinearity is not a problem.

The means and standard deviations for all variables are shown in Table 5 and the comparison of the data from the current study with those of the two Spanish development studies (Losada *et al.*, 2010; Montorio *et al.*, 2009) are reported in Table 6.

Table 5: Means and standard deviations for all variables across relevant groups

| | Caregiver gender | | Caregiver relationship | | Residence | |
|---------------------|------------------|------------------|------------------------|------------------|---------------------------|------------------|
| | Male | Female | Spousal | Adult-child | Lives with care recipient | Lives separately |
| CES-D | 14.76 (8.49) | 20.96 (11.21) | 18.21 (10.25) | 21.68 (12.52) | 18.95 (10.61) | 18.70 (12.31) |
| CGQ | 23.39 (10.91) | 29.83 (15.08) | 26.58 (13.61) | 32.43 (15.81) | 27.13 (13.74) | 31.41 (16.62) |
| DTACQ (16 items) | 29.66 (9.96) | 24.56 (9.54) | 27.13 (9.82) | 23.47 (10.49) | 27.03 (9.88) | 20.72 (7.65) |
| CFQ | 42.56 (9.51) | 45.70 (12.09) | 44.06 (11.15) | 47.18 (11.89) | 44.62 (11.51) | 45.87 (10.44) |
| ZBI guilt factor | 5.29 (2.61) | 5.72 (3.17) | 5.36 (2.96) | 6.45 (2.99) | 5.51 (3.04) | 6.04 (2.65) |
| DAS | 8.32 (5.32) | 8.70 (5.65) | 8.34 (5.39) | 9.53 (6.10) | 8.38 (5.54) | 9.65 (5.43) |

Abbreviations: CES-D = Center for Epidemiological Studies – Depression Scale, CGQ = Caregiver Guilt Questionnaire, DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire, CFQ = Cognitive Fusion Questionnaire, ZBI = Zarit Burden Interview, DAS = Dysfunctional Attitudes Scale

Table 6: Means and standard deviations for all variables for overall sample in British and Spanish samples

| | | <i>M</i> | <i>SD</i> |
|------------------|------------------------|----------|-----------|
| CES-D | Current study | 18.83 | 10.75 |
| | Losada <i>et al.</i> | 18.00 | 11.73 |
| | Montorio <i>et al.</i> | 18.77 | 10.86 |
| CGQ | Current study | 27.61 | 14.10 |
| | Losada <i>et al.</i> | 17.90 | 12.70 |
| | Montorio <i>et al.</i> | - | - |
| DTACQ | Current study | 26.32 | 9.96 |
| | Losada <i>et al.</i> | - | - |
| | Montorio <i>et al.</i> | 29.40 | 12.50 |
| CFQ | Current study | 44.62 | 11.35 |
| | Losada <i>et al.</i> | - | - |
| | Montorio <i>et al.</i> | - | - |
| ZBI guilt factor | Current study | 5.57 | 2.99 |
| | Losada <i>et al.</i> | 4.65 | 3.41 |
| | Montorio <i>et al.</i> | - | - |
| DAS | Current study | 8.57 | 5.53 |
| | Losada <i>et al.</i> | - | - |
| | Montorio <i>et al.</i> | 12.70 | 7.30 |

Abbreviations: CES-D = Center for Epidemiological Studies – Depression Scale, CGQ = Caregiver Guilt Questionnaire, DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire, CFQ = Cognitive Fusion Questionnaire, ZBI = Zarit Burden Interview, DAS = Dysfunctional Attitudes Scale

For the clarity of analysis and reporting, the data from this study are now disaggregated into three parts; the first part reports the psychometric properties of the Caregiver Guilt Questionnaire, the second part focuses on the psychometric properties of the Dysfunctional Thoughts About Caregiving Questionnaire and the third part reports the relationships between dysfunctional thoughts, cognitive fusion, guilt and depression in dementia caregivers.

4.3 Part 1

Research Question 1: What are the psychometric properties of the Caregiver Guilt Questionnaire in a British sample of dementia caregivers?

4.3.1 Factor structure

Principal axis factoring was used to explore the factor structure of the Caregiver Guilt Questionnaire. The Kaiser criterion should not be used to determine how many factors to extract with principal axis factoring⁴ (Russell, 2002) therefore the scree plot, parallel analysis⁵ and Velicer's MAP test⁶ (O'Connor, 2000) were used (Fabrigar *et al.*, 1999; Russell, 2002). The scree plot for the CGQ (shown in Figure 5) suggests the presence of two or five factors. Parallel analysis, conducted using 1000 permutations of the original raw dataset, and Velicer's MAP test both indicated that five factors should be extracted. The five factors extracted are shown in Table 7.

An oblique⁷ (promax) rotation was completed, as it was anticipated that different factors within the CGQ would correlate as they are likely to be related psychological constructs. A promax rotation first conducts an orthogonal (varimax) rotation and then relaxes the criterion that the factors must be uncorrelated. The results of this rotation demonstrated that the factors are correlated (see Table 8), which indicates

⁴ Mathematically, the Kaiser criterion only holds true where the communality of every variable has been estimated to be 1 (i.e. principal components analysis) (Gorsuch, 1983). It should not be used with principal axis factoring to avoid inaccurate factor extraction (Comrey & Lee, 1992).

⁵Parallel analysis generates random data sets from the original data set, with the same number of variables and observations. The eigenvalues from the random data sets are then compared to the eigenvalues from the original data set to determine how many factors to extract. Factors are extracted if the eigenvalue from the original data set is greater than that from the random datasets.

⁶Velicer's MAP test conducts a principal components analysis, and then the first component is partialled out of the correlations between variables. The average squared coefficient is then computed for this partial correlation matrix. The second step follows the same procedure but partials out the first two components. This is repeated one fewer times than the number of variables. The smallest average squared correlation indicates how many factors to extract.

⁷ An oblique rotation allows factors to correlate, whereas an orthogonal rotation requires factors to be independent. Although some researchers prefer orthogonal rotations for their conceptual clarity (Nunnally, 1978 as cited in Fabrigar *et al.*, 1999), where factors are theoretically likely to correlate, an oblique rotation is a more accurate representation of the relationships between factors.

that an oblique rotation is most appropriate (Fabrigar *et al.*, 1999). The factor loadings using the promax rotation are shown in Table 7.

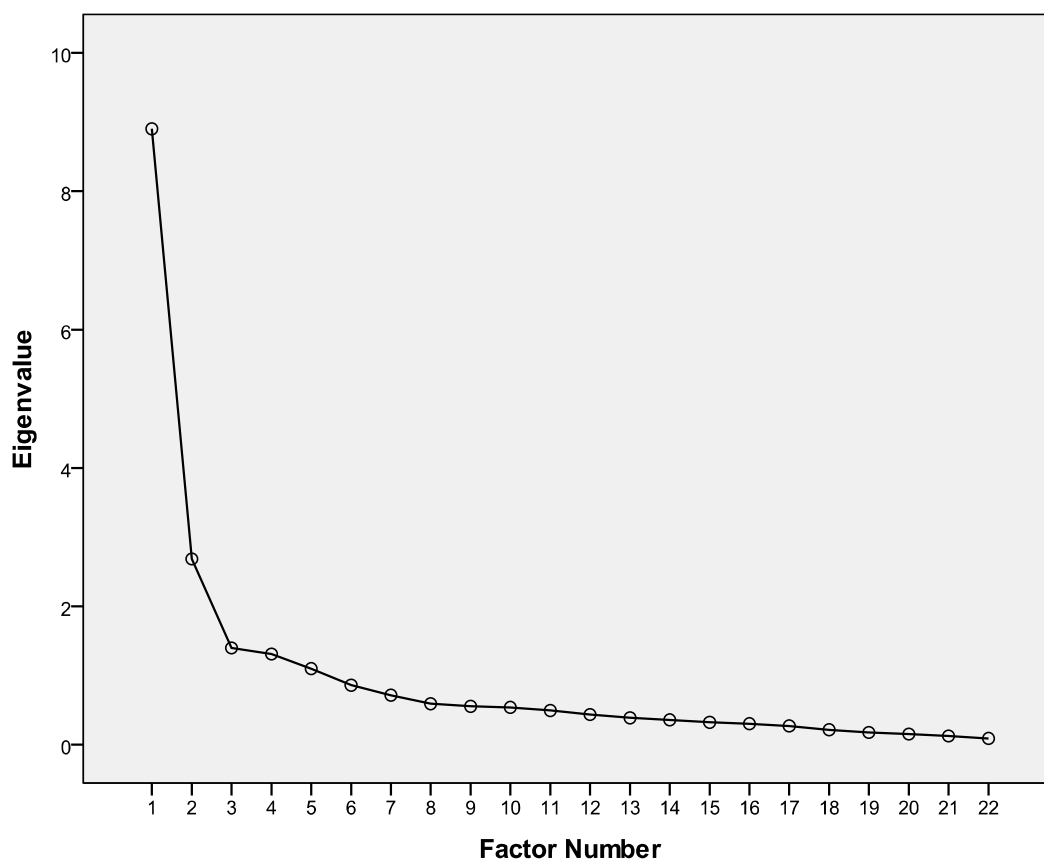


Figure 5: Scree plot of CGQ factors

Table 7: Factor loadings with promax rotation of 22 CGQ items

| CGQ Item | Factor | | | | |
|---|-------------|------------|------|------|------|
| | 1 | 2 | 3 | 4 | 5 |
| 2. I have felt guilty about the way I've sometimes behaved with my relative. | .81 | | | | |
| 8. I have felt bad about things I may have done wrong with the person I'm caring for. | .58 | | | | |
| 10. I have felt bad about getting angry with the person I'm caring for. | 1.14 | -.30 | | | |
| 11. I have felt bad about telling off the person I'm caring for, for some reason. | .88 | | | | |
| 12. I've got angry with myself for having negative feelings towards the person I'm caring for. | .40 | | | | |
| 14. I have felt bad about not having more patience with the person I'm caring for. | .71 | | | | |
| 5. I have thought that I'm not doing things right with the person I'm caring for. | .30 | .46 | | | |
| 6. I have thought that, given the circumstances, I'm doing a good job as a caregiver. | | .40 | | | |
| 9. I have thought that perhaps I'm not caring well for my relative. | | .65 | | | |
| 13. I've found myself thinking that I'm not up to the job. | | .60 | | | |
| 21. I have thought that the way I care for my relative may not be appropriate and may make his/her problem get worse. | | .86 | | | |
| 22. I have felt guilty thinking that my lack of information and preparedness might mean that I'm not handling the care of my relative in the best way possible. | | .85 | | | |
| 17. I have felt guilty about having wished that others "could have this burden" or suffer as I do. | | | .53 | | |
| 18. I have felt like a bad person for hating and/or envying other relatives who could have taken responsibility for some caring and do not do so. | | | 1.02 | | |
| 19. I have felt bad for having negative feelings (e.g. hate, anger or resentment) towards some relatives. | | | .91 | | |
| 20. I have felt guilty about having so many negative emotions in relation to caring. | | | .37 | | |
| 1. I have felt bad about having made some plans or done activities without taking my relative into account. | | | | .32 | |
| 7. When I've gone out to do a pleasant activity (e.g. eating out in a restaurant) I've felt guilty and unable to stop thinking that I should be caring for my relative. | | | | .58 | |
| 15. I have felt bad about leaving my relative in the care of someone else while I do my own things (e.g. work, shopping, going to the doctor). | | | | .80 | |
| 16. I have felt bad for leaving my relative in the care of someone else while I had fun. | | | | 1.01 | |
| 3. I have felt bad for not looking after my other relatives (husband, wife, children...) as I should, due to my caregiving. | | | | | 1.04 |
| 4. I have felt bad about not being able to devote | | | | | .95 |

| | | | | | | |
|--|--------------------------|-------|-------|------|------|------|
| more time to my family (husband, wife, children...) due to my caregiving. | | | | | | |
| Unrotated solution | Sums of squared loadings | 8.54 | 2.43 | 1.12 | 0.96 | 0.81 |
| | % variance explained | 38.83 | 11.02 | 5.10 | 4.36 | 3.69 |
| Rotated solution | Sums of squared loadings | 6.43 | 6.65 | 5.52 | 5.96 | 4.79 |

NB: Loadings <.3 are not shown. Where an item loads on two factors >.3, the loading in bold is the factor to which the item is allocated. See Appendix 11 for all factor loadings. Abbreviation: CGQ = Caregiver Guilt Questionnaire.

Table 8: CGQ factor correlations

| | Factor 1 | Factor 2 | Factor 3 | Factor 4 | Factor 5 |
|----------|----------|----------|----------|----------|----------|
| Factor 1 | 1.00 | | | | |
| Factor 2 | .67 | 1.00 | | | |
| Factor 3 | .37 | .51 | 1.00 | | |
| Factor 4 | .50 | .60 | .58 | 1.00 | |
| Factor 5 | .36 | .50 | .52 | .59 | 1.00 |

Abbreviation: CGQ = Caregiver Guilt Questionnaire.

The factors can be interpreted as ‘guilt about doing wrong by the care recipient’ (Factor 1), ‘guilt about failing to meet the challenges of caregiving’ (Factor 2), ‘guilt over experience of negative emotions in relation to caregiving’ (Factor 3), ‘guilt about self-care’ (Factor 4) and ‘guilt about neglecting other relatives’ (Factor 5). All individual items loaded onto the same factors as reported in the original paper for this measure (Losada *et al.*, 2010) with the exception of item 20, which loaded on Factor 1 in the Spanish sample (guilt about doing wrong by the care recipient) and Factor 3 in the in present study (guilt over experience of negative emotions in relation to caregiving). The third, fourth and fifth factors extracted in this sample were extracted in a different order in the Spanish sample (Losada *et al.*, 2010). Factor 3 in this study (guilt over experience of negative emotions in relation to caregiving) was extracted as the fifth factor in the Spanish study; Factor 4 in this study (guilt about self-care) was extracted as the third factor in the Spanish study; and Factor 5 in this study (guilt about neglecting other relatives) was extracted as the

fourth factor in the Spanish study. Overall, however, the five-factor structure originally reported by Losada *et al.* (2010) is retained with this current sample.

4.3.2 Internal consistency

Internal consistencies, as measured by Cronbach's alpha, for both the UK and Spanish sample are shown in Table 9. Kline, as cited in Clark-Carter (2010), recommends that Cronbach's alpha should be at least .7, preferably .9. The internal consistencies of the whole scale and all five factors are good.

Table 9: Internal consistencies for the CGQ in British and Spanish samples

| Current study | Cronbach's alpha | Losada <i>et al.</i> (2010) | Cronbach's alpha |
|---------------|------------------|-----------------------------|------------------|
| Factor 1 | .90 | Factor 1 | .89 |
| Factor 2 | .80 | Factor 2 | .76 |
| Factor 3 | .85 | Factor 5 | .61 |
| Factor 4 | .84 | Factor 3 | .69 |
| Factor 5 | .94 | Factor 4 | .86 |
| Whole scale | .93 | Whole scale | .88 |

NB: Due to the differences in the order of extraction between the British and Spanish samples, factors are listed in different orders to permit a direct comparison of internal consistencies of the same subscales. Abbreviation: CGQ = Caregiver Guilt Questionnaire.

4.3.3 Clinical cut off

In the initial development study of the CGQ (Losada *et al.*, 2010), a clinical cut off score was not reported. Receiver Operating Characteristics (ROC) analyses were conducted to analyse the association between the CGQ and the presence of a score on the CES-D above the clinical cut off. The area under the curve (AUC) found with ROC analysis was .79 (SE=0.03; 95 per cent confidence intervals [CI] .73-.84; $p<.001$). With a clinical score on the CES-D as the criterion, the cut off score of 22 on the CGQ showed the optimal balance between sensitivity (80 per cent) and specificity (61.5 per cent), with a positive predictive value (PPV) of 70.2 per cent.

4.3.4 Convergent validity

Convergent validity was assessed by correlational analysis with the guilt factor of the ZBI. In order to control for the risk of increasing the Type I error rate by performing multiple post-hoc tests, the Bonferroni correction was applied for the two correlations undertaken, reducing the acceptable p level to .025. The CGQ total score and the ZBI guilt factor correlated positively and significantly ($r = .65$, $p < .001$), indicating that caregivers with a high CGQ total score also had a high ZBI guilt factor score. Each factor of the CGQ also correlated positively and significantly with the ZBI guilt factor, as shown in Table 10.

Table 10: Correlations between ZBI guilt factor and CGQ factors

| | ZBI guilt factor | |
|--------------|------------------|------------|
| | r | p |
| CGQ Factor 1 | .43 | $p < .001$ |
| CGQ Factor 2 | .57 | $p < .001$ |
| CGQ Factor 3 | .53 | $p < .001$ |
| CGQ Factor 4 | .52 | $p < .001$ |
| CGQ Factor 5 | .49 | $p < .001$ |

Abbreviation: CGQ = Caregiver Guilt Questionnaire.

The CGQ total score also correlated significantly with the CES-D total score ($r = .60$, $p < .001$) indicating caregivers reporting high levels of guilt also report high levels of depressive symptoms.

4.3.5 Associations between CGQ and demographic characteristics

Associations between demographic characteristics and the CGQ were examined using independent sample t tests. In order to control for the risk of increasing the Type I error rate by performing multiple post-hoc comparisons, the Bonferroni correction was applied for the two t tests completed, reducing the acceptable p level to .025. Levene's test was used to assess homogeneity of variance and, where this assumption was not met, automatic statistical adjustment was made for the heterogeneity of variance. Means and standard deviations are shown in Table 5. Adult-child caregivers experienced significantly higher levels of guilt, as measured by the CGQ total score ($t(213) = 2.33$, $p < .025$), in comparison to spousal

caregivers. The effect size was small to medium (Cohen, 1992) ($d = 0.41$). Means and standard deviations are shown in Table 5. Female caregivers experienced significantly higher levels of guilt, as measured by the CGQ total score, than male caregivers ($t(197.30) = 3.64, p < .001$). The effect size was small to medium (Cohen, 1992) ($d = 0.46$).

4.4 Part 2

Research Question 2: What are the psychometric properties of the Dysfunctional Thoughts About Caregiving Questionnaire in a British sample of dementia caregivers?

4.4.1 Factor structure and internal consistency

Principal axis factoring was used to explore the factor structure of the Dysfunctional Thoughts About Caregiving Questionnaire (DTACQ). As for the CGQ, the scree plot, parallel analysis and Velicer's MAP test were used to determine how many factors to extract. The scree plot for the DTACQ is shown in Figure 6, and suggests a two or three factor solution. Velicer's MAP test indicated a one factor solution, and parallel analysis, conducted using 1000 permutations of the original raw dataset, suggested a four factor solution. It is recommended that when the result of a MAP test and parallel analysis differ, the table of average squared partial correlations should be examined for close results and the parallel analysis should be rerun with a larger number of permutations (O'Connor, 2000). A repeat of the parallel analysis using 10000 permutations of the original raw dataset again suggested a four factor solution. In the MAP test, the smallest average squared partial correlation was .17 on step number one, indicating a one factor solution. However the average squared partial correlation on step two was only slightly larger at .18, which suggests that a two factor solution may also be appropriate. As the MAP test errs on the side of underestimating factors, and parallel analysis errs on the side of overestimating factors, it was thought that a two or three factor solution may be plausible. Comrey

and Lee (1992) recommend that when the number of factors to extract is unclear, it is preferable to extract a greater number of factors and discard any that do not make a significant contribution to the factor solution after rotation. Therefore principal axis factoring was conducted forcing a three factor solution, and the total variance explained by each factor was examined.

Details of the three factor solution are shown in Appendix 12. The three factors could be interpreted as ‘avoidance of help-seeking’ (Factor 1), ‘self-sacrifice and total devotion to care recipient’s needs’ (Factor 2), and ‘perfectionism’ (Factor 3). In the three factor solution, the third factor explained relatively little additional variance (3.39 per cent), which was not felt to be sufficient to justify retention of the factor. In addition, in the three factor solution seven items had significant cross-loadings, in comparison to only one item in the two factor solution, which suggests that the three factor solution does not have good simple structure. Comparing the three and two factor solutions, all items (except item 12) from Factor 1 and Factor 2 of the three factor solution combine to form Factor 1 in the two factor solution. This suggests that Factor 1 and Factor 2 in the three factor solution may not represent truly unique factors. Conceptual overlap can be seen between ‘avoidance of help-seeking’ (Factor 1), ‘self-sacrifice and total devotion to care recipient’s needs’ (Factor 2). In light of the improved simple structure and the small amount of variance explained by the third factor, a two factor solution was accepted for the DTACQ.

As with the CGQ, it was anticipated that different factors within the DTACQ would correlate as they are likely to be related psychological constructs, making an oblique rotation more appropriate. A promax rotation was completed and demonstrated that the factors are correlated (see Table 11). The factor loadings using the promax rotation are shown in Table 12. Factor 1 can be interpreted ‘perception of sole responsibility’ and Factor 2 ‘perfectionism’, as in the Spanish development study (Montorio *et al.*, 2009). The factor structure identified in this study is highly congruent with the factor structure reported in the original paper for this measure,

with the exception of item 15 ('A caregiver should only seek help from others when he/she does not know how to solve a problem.') which loaded on Factor 2 in the Spanish sample and Factor 1 in the present study. Overall the two factor structure originally reported by Montorio *et al.* (2009) is retained with this current sample.

Figure 6: Scree plot of DTACQ factors

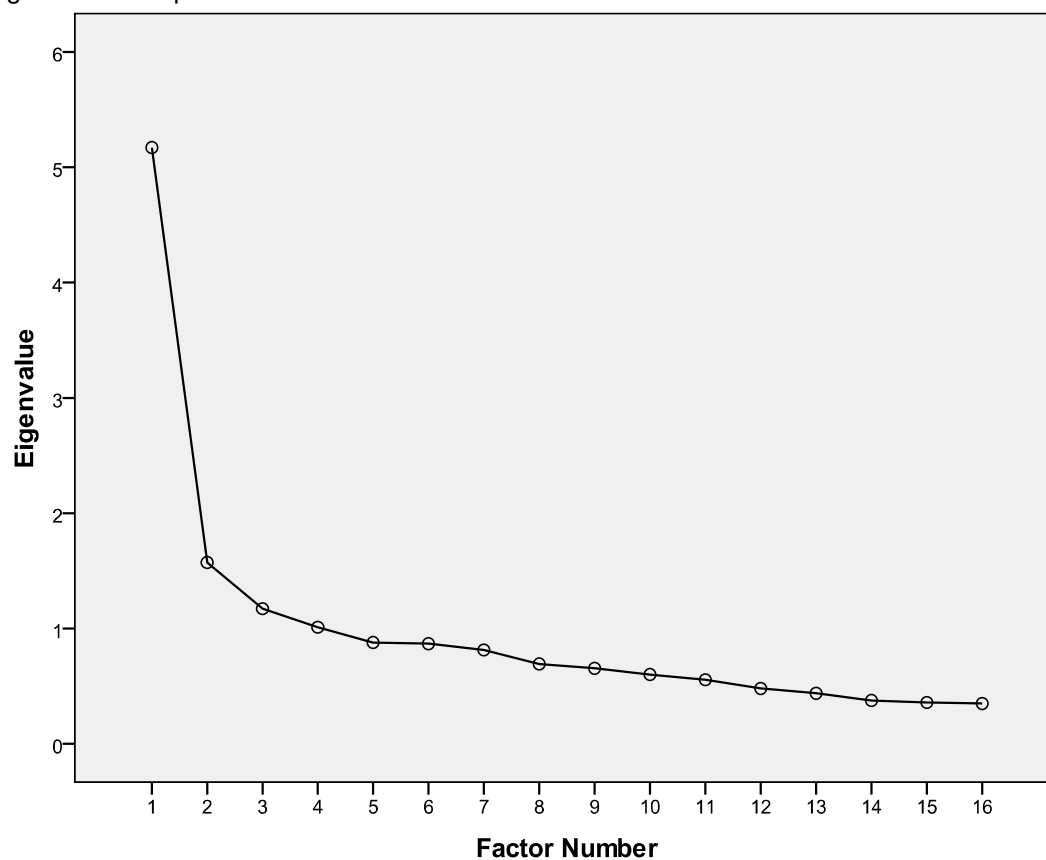


Table 11: DTACQ factor correlation

| | Factor 1 | Factor 2 |
|----------|----------|----------|
| Factor 1 | 1.00 | .53 |
| Factor 2 | .53 | 1.00 |

Abbreviation: DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire

Table 12: Factor loadings with promax rotation of 16 DTACQ items

| DTACQ Item | Factor | |
|--|--------------------------|-------|
| | 1 | 2 |
| 1. No matter how badly a caregiver feels, he/she should not vent with others because it would be disrespectful to the person being cared for. | .32 | |
| 2. Caregivers should avoid talking about their problems with others because others have their own lives and don't need to be bothered with more problems. | .63 | |
| 3. When a person takes care of a frail/sick relative, he/she should set aside his/her interests, and dedicate himself/herself completely to the care of the frail/sick relative. | .69 | |
| 4. A caregiver should only seek help from others or find other alternatives when the caregiving situation is at its worst or when he/she can no longer handle it. | .82 | |
| 5. Asking for help from people who are not part of the family is the last thing that a caregiver should do because caring for a frail/sick relative should be handled by the family. | .73 | |
| 6. As a caregiver, I feel that I should do everything that my frail/sick relative asks me to do, even though I might believe it is excessively demanding. | .57 | |
| 7. It is selfish for a caregiver to dedicate time to himself/herself when a relative is frail/sick and needs care. | .63 | |
| 8. It is logical for caregivers to give up their own needs, setting aside their own life satisfaction, in favour of their relative's needs. | .47 | |
| 9. A good caregiver is one that helps his/her relative with all tasks, including those that the relative can do for himself/herself, if it makes life easier for the relative. | .40 | |
| 10. Only the closest person to the frail/sick older adult knows how to truly take care of him/her. | .56 | |
| 15. A caregiver should only seek help from others when he/she does not know how to solve a problem. | .53 | |
| 11. A good caregiver should never get mad or lose control with the person that is being cared for. | | .55 |
| 12. If a caregiver has feelings of embarrassment and rejection towards his/her relative, it's because the caregiver is failing in some way with his/her caregiving duties. | | .30 |
| 13. Good caregivers should remain happy and in good spirits all day long to deal adequately with the daily tasks of caregiving. | | .71 |
| 14. To become a good caregiver would mean not making mistakes when taking care of a frail/sick relative. | | .61 |
| 16. It would be unforgivable for a caregiver to think "it would be better for everyone if my relative died". | | |
| Unrotated solution | Sums of squared loadings | 4.56 |
| | % variance explained | 28.53 |
| Rotated solution | Sums of squared loadings | 4.41 |
| | % variance explained | 2.68 |

NB: Loadings <.3 are not shown. Item 16 did not load on either factor above .3. See Appendix 13 for all factor loadings. Abbreviation: DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire

As can be seen in Table 12, items 12 and 16 do not load on either factor above .3. Item 12 has a loading on Factor 1 of .19 and on Factor 2 of .30. Item 16 has a

loading on Factor 1 of -.11 and Factor 2 of .27. Both items load most strongly on Factor 2. The weak factor loadings indicate that these two items may not be of substantive importance to Factor 2, and the factor solution may be improved by their removal.

Internal consistencies, as measured by Cronbach's alpha, are shown in Table 13. Kline, as cited in Clark-Carter (2010), recommends that Cronbach's alpha should be at least .7, preferably .9. The whole scale and Factor 1 show adequate internal consistency, however the internal consistency of Factor 2 is low.

Table 13: Internal consistencies for 16 item DTACQ in British and Spanish samples

| | Cronbach's alpha | |
|-------------|------------------|-------------------------------|
| | Current study | Montorio <i>et al.</i> (2009) |
| Factor 1 | .85 | .86* |
| Factor 2 | .58 | .78* |
| Whole scale | .84 | .89 |

NB: * denotes that although relating to the same sample, these figures are reported in Losada *et al.* (2006). Abbreviation: DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire

The removal of item 12 would reduce the total scale alpha to .84 and Factor 2 alpha to .54. The removal of item 16 would improve the total scale alpha to .86 and Factor 2 alpha to .65. Therefore item 16 was removed initially, and principal axis factoring with promax rotation was repeated, extracting a two factor solution. Items loaded on the same factors as in the previous factor analysis. Factor loadings are shown in Table 14. Each item loaded on the same factor as in the previous principal axis factoring and with the removal of item 16, the factor loading of item 12 increased to .32. Item 12 was therefore retained in the factor solution. Subsequent analyses in this study use the 15 item DTACQ.

Table 14: Factor loadings with promax rotation of 15 DTACQ items

| DTACQ Item | Factor | |
|--|--------------------------|-------|
| | 1 | 2 |
| 1. No matter how badly a caregiver feels, he/she should not vent with others because it would be disrespectful to the person being cared for. | .31 | |
| 2. Caregivers should avoid talking about their problems with others because others have their own lives and don't need to be bothered with more problems. | .65 | |
| 3. When a person takes care of a frail/sick relative, he/she should set aside his/her interests, and dedicate himself/herself completely to the care of the frail/sick relative. | .66 | |
| 4. A caregiver should only seek help from others or find other alternatives when the caregiving situation is at its worst or when he/she can no longer handle it. | .83 | |
| 5. Asking for help from people who are not part of the family is the last thing that a caregiver should do because caring for a frail/sick relative should be handled by the family. | .73 | |
| 6. As a caregiver, I feel that I should do everything that my frail/sick relative asks me to do, even though I might believe it is excessively demanding. | .52 | |
| 7. It is selfish for a caregiver to dedicate time to himself/herself when a relative is frail/sick and needs care. | .61 | |
| 8. It is logical for caregivers to give up their own needs, setting aside their own life satisfaction, in favour of their relative's needs. | .44 | |
| 9. A good caregiver is one that helps his/her relative with all tasks, including those that the relative can do for himself/herself, if it makes life easier for the relative. | .35 | |
| 10. Only the closest person to the frail/sick older adult knows how to truly take care of him/her. | .53 | |
| 15. A caregiver should only seek help from others when he/she does not know how to solve a problem. | .53 | |
| 11. A good caregiver should never get mad or lose control with the person that is being cared for. | | .58 |
| 12. If a caregiver has feelings of embarrassment and rejection towards his/her relative, it's because the caregiver is failing in some way with his/her caregiving duties. | | .32 |
| 13. Good caregivers should remain happy and in good spirits all day long to deal adequately with the daily tasks of caregiving. | | .74 |
| 14. To become a good caregiver would mean not making mistakes when taking care of a frail/sick relative. | | .61 |
| Unrotated solution | Sums of squared loadings | 4.56 |
| | % variance explained | 30.38 |
| Rotated solution | Sums of squared loadings | 4.35 |
| | % variance explained | 2.86 |

NB: Loadings <.3 are not shown. See Appendix 14 for all factor loadings. Abbreviation: DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire

4.4.2 Convergent validity

Convergent validity was assessed by correlational analysis with the DAS and the CES-D. In order to control for the risk of increasing the Type I error rate by performing multiple post-hoc comparisons, the Bonferroni correction was applied for

the three correlations undertaken, which reduced the acceptable p level to .017. The DTACQ total score correlated significantly ($r = .25$, $p < .001$) with the DAS total score; those caregivers scoring highly on the DTACQ also scored highly on the measure of dysfunctional attitudes. The DTACQ total score did not correlate significantly with the CES-D total score ($r = .09$, $p > .05$) as would be theoretically predicted. This correlation was repeated in a sub sample of participants who scored above the clinical cut off for depressive disorder on the CES-D. Again, the DTACQ total score did not correlate significantly with the CES-D total score ($r = .02$, $p > .05$). Construct validity was assessed by correlational analysis with the amount of help received. The DTACQ total score showed a significant negative correlation with the number of sources of help received by the caregiver ($r = -.19$, $p < .01$). Construct validity was also assessed by comparing the DTACQ scores of those caregivers scoring above and below the clinical cut-off on the CES-D. In order to control for the risk of increasing the Type I error rate by performing multiple post-hoc comparisons, the Bonferroni correction was applied for the three t tests completed, reducing the acceptable p level to .017. An independent samples t test found no significant difference between the DTACQ scores between caregivers above and below the clinical cut-off on the CES-D ($t(219) = .82$, $p > .05$).

4.3.3 Associations between DTACQ and demographic characteristics

Associations between demographic characteristics and the DTACQ were examined using independent sample t tests. Levene's test was used to assess the homogeneity of variance and, where this assumption was not met, automatic adjustment was made for the heterogeneity of variance. Means and standard deviations are shown in Table 5. Male caregivers experience significantly higher levels of dysfunctional thoughts, as measured by the DTACQ ($t(219) = 3.42$, $p < .001$). The effect size was small to medium (Cohen, 1992) ($d = 0.47$). Spousal caregivers experienced higher levels of dysfunctional thoughts than adult-child caregivers as measured by the DTACQ, however after applying the Bonferroni correction, this difference was no longer significant ($t(213) = 2.14$, $p > .017$).

4.5 Part 3

Research Question 3: Are caregiver guilt, dysfunctional thoughts about caregiving and cognitive fusion significant predictors of caregiver depression?

Variables were entered hierarchically into a multiple regression model, based on established theoretical associations in the literature. Guilt has been shown to be associated with depression (Kim *et al.*, 2011) and is one of the diagnostic criteria for major depressive disorder in DSM-IV (American Psychiatric Association, 2000) therefore guilt was entered into the regression model first. It is well established in the literature that dysfunctional thoughts and attitudes are associated with depressive symptoms (Haaga *et al.*, 1991; Kwon & Oei, 1992; Weissman & Beck, 1978) however the DTACQ did not correlate with the CES-D. This prevented research question three being fully tested, as due to the limitations of the DTACQ, a reliable and valid measure of dysfunctional beliefs about caregiving was not available for inclusion in the regression model. However the DAS, a previously validated measure of dysfunctional attitudes, which are hypothesised to be related to both dysfunctional thoughts and depressive symptoms, was available thus still permitting the inclusion of a predictor from the cognitive behavioural model. The DAS correlated significantly with the CES-D ($r = .22$, $p < .01$). Therefore, the DAS was used and entered into the regression model second. As there is less research investigating the association between cognitive fusion and depression, this variable was entered last.

Table 15 illustrates that all three levels of the regression model were significant and explained up to 50 per cent of variance in caregiver depression, as measured by the CES-D. Both guilt and cognitive fusion made significant unique contributions to the variance in caregiver depression scores, but dysfunctional attitudes did not. As dysfunctional attitudes were statistically redundant in this model, the hierarchical regression was repeated with guilt entered first and then cognitive fusion, the results of which are shown in Table 16. Again, both levels of the regression model were

significant and explained 50 per cent of the variance in caregiver depression. Although both guilt and cognitive fusion were significant predictors of variance in caregiver depression, when cognitive fusion was entered into the regression model, it made a larger contribution to the model than guilt. Hypotheses 1 and 3 were supported, Hypothesis 2 was rejected.

Table 15: Hierarchical regression models including guilt, dysfunctional attitudes and cognitive fusion

| Step | Predictor variables | <i>t</i> | R | R ² | <i>F</i> | R ² change | <i>F</i> change |
|------|---------------------|----------|-----------------|----------------|----------|-----------------------|-----------------|
| 1 | CGQ | .60 | 11.19 * | .60 | .36 | 125.14 * | 125.14 * |
| 2 | CGQ | .59 | 10.47 * | .61 | .37 | 63.38 * | 1.39 <i>ns</i> |
| | DAS | .07 | 1.18 <i>ns</i> | | | | |
| 3 | CGQ | .33 | 5.43 * | .71 | .50 | 71.33 * | 55.53 * |
| | DAS | -.00 | -.073 <i>ns</i> | | | | |
| | CFQ | .46 | 7.45 * | | | | |

NB: * significant at $p < .001$, *ns* = not significant. A significant *F* value indicates that the model is significant. A significant *F* change value indicates that there is a significant increase in variance accounted for by the model. A significant *t* value indicates that the predictor variable makes a significant contribution to the model. Abbreviations: CES-D = Center for Epidemiological Studies – Depression Scale, CGQ = Caregiver Guilt Questionnaire, DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire, CFQ = Cognitive Fusion Questionnaire, ZBI = Zarit Burden Interview, DAS = Dysfunctional Attitudes Scale

Table 16: Hierarchical regression models including guilt and cognition fusion

| Step | Predictor variables | <i>t</i> | R | R ² | <i>F</i> | R ² change | <i>F</i> change |
|------|---------------------|----------|---------|----------------|----------|-----------------------|-----------------|
| 1 | CGQ | .60 | 11.19 * | .60 | .36 | 125.14 * | 125.14 * |
| 2 | CGQ | .33 | 5.47 * | .71 | .50 | 107.48 * | 57.53 * |
| | CFQ | .46 | 7.59 * | | | | |

NB: * significant at $p < .001$, *ns* = not significant. A significant *F* value indicates that the model is significant. A significant *F* change value indicates that there is a significant increase in variance accounted for by the model. A significant *t* value indicates that the predictor variable makes a significant contribution to the model. Abbreviations: CES-D = Center for Epidemiological Studies – Depression Scale, CGQ = Caregiver Guilt Questionnaire, DTACQ = Dysfunctional Thoughts about Caregiving Questionnaire, CFQ = Cognitive Fusion Questionnaire, ZBI = Zarit Burden Interview, DAS = Dysfunctional Attitudes Scale

5 Discussion

This study addresses three principal research questions; (1) to establish the psychometric properties of the Caregiver Guilt Questionnaire (CGQ) in a British sample of dementia caregivers, (2) to establish the psychometric properties of the Dysfunctional Thoughts About Caregiving Questionnaire (DTACQ) in a British sample of dementia caregivers and (3) to test caregiver guilt, dysfunctional thoughts and cognitive fusion as predictors of depression in dementia caregivers. To the best of the author's knowledge, there are no studies examining either the psychometric structures of the CGQ and DTACQ in an English-speaking population, or the relationship between cognitive fusion and depression in dementia caregivers. The results of this study will be discussed in the context of the current research literature, as well as considering clinical implications, limitations of the findings and directions for future research.

5.1 Comparison of British and Spanish samples

Several key differences between the British and Spanish samples should be noted. There was a greater proportion of spousal caregivers in the UK sample in comparison to the two Spanish samples (80.5 per cent cf. 37.2 per cent and 44.1 per cent). Bond *et al.* (1999) conducted a large scale survey ($n = 1127$) of informal caregivers of physically or mentally frail older people in England. Of all the older people, who identified a key informal caregiver ($n = 884$), the caregiver was most commonly a spouse (39 per cent) or an adult-child (39 per cent). This suggests that spousal caregivers are relatively over-represented in this study in comparison to caregivers in the general population. A recent meta-analysis (Pinquart & Sorensen, 2011) found that spousal caregivers reported significantly higher levels of depressive symptomatology than adult children; however, the mean depression score was very similar across the British and two Spanish samples, despite the differences in demographic characteristics.

The British sample contained substantially more male caregivers (34.4 per cent cf. 20.8 per cent and 24.7 per cent). Caregivers in the current study were more highly educated (13.4 years education cf. 8.7) than those in the Spanish studies. This may be an artefact of the recruitment methods; Losada *et al.* (2010) and Montorio *et al.* (2009) recruited from local health and social care centres, whereas caregivers in the current study were principally recruited from a research register, on which caregivers with a higher education level may be more likely to enrol. Recruitment strategies may also explain the gender differences in samples; research has shown that men show less help-seeking behaviour than women (Galdas *et al.*, 2005) therefore a strategy which seeks to recruit caregivers through the services that they receive, as used by Montorio *et al.* (2009) and Losada *et al.* (2010) is less likely to recruit large numbers of men. This study recruited through a research register, which is not dependent on service use, which may explain the greater proportion of male caregivers in this sample. Pinquart and Sorensen (2011) also found that spousal caregivers are more likely to be male; therefore the higher number of spousal caregivers in this sample may also explain the greater number of male caregivers.

5.2 Caregiver Guilt Questionnaire (CGQ)

The CGQ (Losada *et al.*, 2010) was designed to measure feelings of guilt experienced by dementia caregivers. The initial development study found that the CGQ measured multiple facets of guilt; the five-factor structure found in the Spanish sample (Losada *et al.*, 2010) was replicated in this study. The five factors were interpreted as ‘guilt about doing wrong by the care recipient’ (Factor 1), ‘guilt about failing to meet the challenges of caregiving’ (Factor 2), ‘guilt over experience of negative emotions in relation to caregiving’ (Factor 3), ‘guilt about self-care’ (Factor 4) and ‘guilt about neglecting other relatives’ (Factor 5). Individual items loaded onto the same factors in the British and Spanish samples, with the exception of item 20 (I have felt guilty about having so many negative emotions in relation to caring). In the Spanish sample, this loaded most strongly onto Factor 1 ‘guilt about doing wrong by care recipient’; however, it also cross-loaded onto Factor 2 ‘guilt about failing to meet the challenges of caregiving’. In the British sample, it loaded onto

Factor 3 ‘guilt about experience of negative emotions in relation to caregiving’, with which it appears to have greater face validity. Although the original Spanish scale was translated into English and back-translated, it is possible that this item may have different nuances in English and Spanish.

Although the same five factors were identified within the British and Spanish samples, the order in which they were extracted differed between the two samples. ‘Guilt over experience of negative emotions in relation to caregiving’ was extracted as the third factor in the British sample whereas it was extracted fifth in the Spanish sample, indicating that this is a relatively more important facet of guilt within the factor model in British caregivers. This may be as a result of cultural differences or the methodology employed. Losada *et al.* (2010) used face to face interviews for completion of the CGQ; Spanish caregivers may have been less willing to acknowledge negative emotions to another person, whereas British caregivers may have acknowledged the presence of negative emotions more easily due to the anonymity of a postal study.

The extraction of the same five factors across the two samples suggests that these are universal themes within the feelings of guilt experienced by dementia caregivers, irrespective of cultural context. These factors highlight the different levels at which caregivers experience guilt: in relation to their behaviours, in relation to their appraisal of their actions and in relation to their emotional experience. This gives an indication of the ways in which feelings of guilt may be alleviated in caregivers; through caregiver training programmes (in order to learn the most effective caregiving strategies and techniques), cognitive behavioural therapy (in order to examine the realism and utility of caregiving appraisals) and peer support (in order to normalise the strong emotions which are often experienced by caregivers).

Data screening identified a pattern of missing data for the CGQ. Three items had more than 5 per cent of responses missing: items 7 ($n = 13$), 15 ($n = 14$) and 16 ($n = 21$), which all refer to the caregiver going out without the care recipient. No missing data are reported in the Spanish development study (Losada *et al.*, 2010), as the questionnaire was completed during a face to face interview. The pattern of missing data in the UK sample suggests that these items do not function well for all caregivers, some of whom said that they simply do not go out without the care recipient, indicating a pattern of subjugating their own needs to those of the person with dementia. These items all load onto Factor 4, '*guilt about attending to own needs*'. Clinically, it is likely that these items would still be useful even if the caregiver does not go out without the care recipient, as this could generate a constructive discussion of factors preventing the caregiver having time alone, which is likely to impact on their quality of life and psychological wellbeing. Given that items loading onto Factor 4 are more likely to be left unanswered, it is important that caution is used when calculating factor subtotals in clinical or research settings.

Factor 5, '*guilt about neglecting other relatives*', only has two items loading onto it in the British sample. This was also found in the Spanish development study (Losada *et al.*, 2010). This aspect of guilt is conceptually different to the other four factors, as it relates to the caregiver's role in the wider family system rather than on the caregiver's behaviour in relation to the person with dementia. This factor contributes significantly to the total variance accounted for by the factor model; however, it is not a well-defined factor with only two items. In order to develop this into a well defined factor, further items should be investigated for inclusion. As levels of familism in the UK are likely to be lower than those in Spain, further items to be tested for inclusion in Factor 5 could include guilt about neglecting other significant relationships outside the family, such as friends or colleagues.

The internal consistency of the CGQ scale and its five factors in the UK sample are all good. All of the Cronbach's alphas are superior to those found in the Spanish

development study (Losada *et al.*, 2010). Based on the alpha values, this suggests that the total scale and subscales are reliable. Convergent validity was established; caregivers reporting higher levels of guilt on the CGQ also reported higher levels of guilt on the ZBI guilt factor and higher levels of depressive symptomatology on the CES-D, as hypothesised. These results do not give an indication of causality; higher levels of guilt could be a consequence of depression, as well as a precursor to it.

This study also sought to establish a clinical cut-off for the CGQ, which the initial development study did not do. ROC analyses indicated that the optimal cut off was 22, to balance specificity and sensitivity (80 per cent and 61.5 per cent respectively). Caregivers scoring 22 or above on the CGQ are likely to show clinical levels of depressive symptomatology (as measured by the CES-D). This cut off is relatively low in comparison to the possible total score of 88. On examination of the data distribution, a slight positive skew is evident in caregivers' responses. Caregivers did not use the full range of the scale and endorse the highest possible levels of guilt. Even though the caregivers in this sample had a higher mean score for guilt than in the Spanish sample (27.61 [14.10] c.f. 17.90 [12.70]), this was still low in comparison to the level of emotionality which could have been endorsed. This may explain why a relatively low cut off provided the optimal sensitivity and specificity. Higher cut offs were considered; however, this quickly reduced the sensitivity of the measure.

It is important to note that the measure of depression used was an epidemiological measure, rather than a clinical diagnostic tool, therefore a score above the cut-off on the CGQ does not necessarily indicate the presence of a major depressive episode, but highlights a potentially treatable pattern of maladaptive cognition, emotion and behaviour, which may be associated with depression. As highlighted by Zarit and Femia (2008), 50 – 80 per cent of caregiving samples do not show clinically significant symptoms of depression; however, guilt is a common experience of caregivers (Gonyea *et al.*, 2008; Rosa *et al.*, 2010; Samuelsson *et al.*, 2001) and may

have an impact on self-care and use of social support (Losada *et al.*, 2010). Longitudinal studies are required to establish causation and mediation; however, early interventions targeting caregiver guilt and its associated maladaptive cognitions and behaviours may lead to improvements in caregivers' psychological wellbeing before the development of a major depressive episode.

As hypothesised, adult-child caregivers reported higher levels of guilt on the CGQ than spousal caregivers. This is consistent with other studies in this field (e.g. Ankri *et al.*, 2005; Losada *et al.*, 2010). This finding is commonly attributed to adult-child caregivers being more likely to live separately from the care recipient, as well as to a greater likelihood of role strain, due to a greater number of competing demands (e.g. employment, caring for young children) (Yee & Schulz, 2000).

As well as the relative neglect of caregiver guilt in the research literature, variables associate with caregiver guilt have also been under researched. Female caregivers, irrespective of their relationship to the care recipient, reported higher levels of guilt than male caregivers, as hypothesised. Losada *et al.* (2010) also found that female caregivers reported higher levels of guilt than male caregivers on the CGQ. Gender differences in psychological outcomes for caregivers have been attributed to differences in caregiving norms, that there is a stronger norm for caregiving and nurturing for women (Raschick & Ingersoll-Dayton, 2004). This may explain higher levels of self-reported guilt in female caregivers, if they perceive that they have transgressed these norms.

5.2 Dysfunctional Thoughts About Caregiving Questionnaire (DTACQ)

The DTACQ was designed to provide a caregiving specific measure of dysfunctional thoughts, conceptualised within a cognitive model as rigid or inappropriate

contingencies guiding an individual's behaviour, which may act as cognitive barriers to a caregiver taking care of their own physical and psychological wellbeing (Losada, Montorio, Knight *et al.*, 2006). The initial development study (Montorio *et al.*, 2009) identified a two factor structure within the DTACQ, which was also replicated in this study: *Perception of sole responsibility* (Factor 1) and *Perfectionism* (Factor 2). Individual DTACQ items loaded onto the same factors in the British and Spanish samples, with the exception of item 15 (A caregiver should only seek help from others when he/she does not know how to solve a problem), which loaded onto *Perfectionism* in the Spanish sample and *Perception of sole responsibility* in the current study. Item 15 appears to have greater face validity with *Perception of sole responsibility*; however, it is possible to see some overlap with the concept of perfectionism. Item 15 showed little cross loading in the British sample (.53 on Factor 1 and .14 on Factor 2), suggesting that this item more strongly reflects the concept of sole responsibility for caregiving for British caregivers. Cross loadings are not reported for the Spanish sample, preventing comparisons.

Item 16 (It would be unforgivable for a caregiver to think “It would be better for everyone if my relative died”) did not function well in this study. This is a very provocative item, likely to arouse strong emotions in caregivers. In clinical use, this item may lead some caregivers to identify with the positive aspects of the caregiving relationship, for both caregiver and care recipient, whilst for other caregivers this item may represent a way of acknowledging what feels impossible to say. In either case, a discussion of the caregiver's response is likely to be informative in the therapeutic context.

Within a research context however, the psychometric properties of all items must be adequate and Item 16 does not function satisfactorily, with small loadings on both factors (-.11 for Factor 1 and .27 for Factor 2 in the British sample). It is also relatively isolated within the questionnaire, with no other items leading up to this statement (e.g. “I wish I didn't have to care for my relative any more” or “It would

be unforgivable for a caregiver to think ‘my relative has a terrible quality of life’”). This item may have functioned better with other items around it also relating to the wish to stop caring, and the thought that the care recipient may suffer less if their life ended. Item 16 does not function well enough in this sample to be included in the UK validation of the DTACQ and was therefore removed from the questionnaire for all further analyses.

Internal consistencies for the total DTACQ scale and Factor 1 are both good, (.84 and .85 respectively), suggesting that the total scale and Factor 1 are reliable. However, Cronbach’s alpha for Factor 2 was not adequate ($\alpha = .58$ in the British sample, c.f. $\alpha = .78$ in Montorio *et al.*, 2009). This suggests that the concept of caregiving perfectionism as measured by DTACQ items is not as reliable in the British sample. One possible explanation for the differences in the alpha for Factor 2 between the UK and Spain is the nature of the samples. Spanish caregivers were recruited through their contact with services, whereas the British caregivers were recruited through a research network and were not necessarily in contact with services. It may be that more perfectionistic caregivers seek contact with services in order to attain the high standards of care that they have set themselves, or that contact with services may prime caregivers to feel that they are not performing adequately and must attain higher standards as a caregiver.

Only four items load onto Factor 2, which is also not enough for it to be a well defined factor (MacCallum *et al.*, 1999). This factor may benefit from being revised, with additional items piloted to better capture dimensions of caregiving perfectionism. The 15 item DTACQ correlates positively and significantly with the DAS as predicted to establish convergent validity, however, the correlation between the DTACQ and DAS total scores was stronger in the Spanish development study ($r = .58$ in the Spanish sample c.f. $r = .25$ in the British sample). This indicates that in a sample of British caregivers, the DTACQ is not as strongly related to general dysfunctional attitudes as in a sample of Spanish caregivers.

It has been proposed that dysfunctional thoughts may influence caregiver distress by limiting caregivers' use of caregiving supports (Losada, Montorio, Knight *et al.*, 2006); some research has found evidence of caregivers' beliefs and attitudes influencing service use (Arai *et al.*, 2000; Pedlar & Biegel, 1999). There was a significant negative correlation between the DTACQ and the amount of help received, which was also found in the Spanish development study (Montorio *et al.*, 2009), although it was small ($r = -.19$, $p < .01$ in the British sample c.f. $r = -.25$, $p < .001$ in the Spanish sample). The weakness of this effect may reflect the relatively simple way in which the amount of help received was measured. Caregivers were simply asked about the number of sources of help; the adequacy of the support and satisfaction with the support received was not measured. It is also possible that other factors, such as social isolation or poverty, have a more influential role in the amount of help received than dysfunctional thoughts about caregiving. The weak convergent validity with the DAS and weak association with amount of help received suggests that the validity of the DTACQ is not adequate at present.

The apparently paradoxical finding that the DTACQ did not correlate significantly with depression scores, as measured by the CES-D, is of particular interest. In addition, there was no significant difference in the DTACQ score between caregivers showing clinical and non-clinical levels of depressive symptomatology, as measured by the CES-D, as found for female caregivers in the Spanish development study (Montorio *et al.*, 2009). This non-significant result was true for the whole sample of British caregivers, as well as subsamples of female only and male only caregivers. The mean score on the CES-D was similar in the British and Spanish samples (18.83 [10.75] in the British sample c.f. 18.77 [10.86] in the Spanish sample), as was the mean DTACQ score (UK: 26.32 [9.96] c.f. Spain: 29.4 [12.5]). The lack of a significant correlation between the DTACQ and the CES-D is not therefore likely to be due to skewed scores in the UK sample as compared to the Spanish sample. As no significant relationship was found between the DTACQ and the CES-D, a ROC analysis could not be completed to establish a clinical cut-off for the DTACQ.

Upon close examination of the DTACQ items, the immediate consequence of such dysfunctional thoughts about caregiving may not be increased or decreased depressive symptoms. Avoidance of help from others, as well as perfectionistic standards, may be more likely to lead to exhaustion, role strain or poor self-care. This, in turn, may then lead to depressive symptomatology. However in this more distant relationship, there is the potential for numerous other factors (such as the presence of supportive significant others or the number of other dependents) to moderate these effects, thus weakening the potential indirect relationship between dysfunctional thoughts, exhaustion and role strain, and depressive symptoms.

Cultural differences may contribute to the lack of a relationship between the DTACQ and CES-D scores in the British sample, as compared to the Spanish sample. Knight *et al.* (2000) have suggested a sociocultural stress and coping model of caregiving, whereby race and ethnicity can influence each stage of the stress and coping model. For example, cultural values can affect who is seen as responsible for caregiving, whether caregiving is appraised as stressful and what coping styles are seen as permissible for caregivers. One such cultural value widely acknowledged to be part of Hispanic culture is that of familism, the strong attachment to family and strong feelings of loyalty, reciprocity and solidarity within the family (Sabogal *et al.*, 1987). High levels of dysfunctional thoughts may be related to depressive symptomatology in a Hispanic sample as these thoughts violate the social norm of familism. Familism may be a weaker social norm in Scottish culture, which is one possible explanation for the absence of a significant correlation between levels of dysfunctional thoughts about caregiving and depressive symptoms. Although Scottish caregivers had a similar mean score on the DTACQ to Spanish caregivers, the perception of sole responsibility may be associated with less distress, as it does not violate a social norm of familism in Scottish culture.

Consistent with the Spanish development study (Montorio *et al.*, 2009), the current study found a significant relationship between gender and DTACQ scores: male caregivers had significantly higher scores on the DTACQ than female caregivers (29.66 [9.96] and 24.56 [9.54] respectively). However, male caregivers had significantly lower scores than female caregivers on the CES-D (14.76 [8.49] and 20.96 [11.21] respectively). Male caregivers also had lower scores than female caregivers on the CES-D in the Spanish sample (16.15 [9.42] and 19.59 [11.17] respectively) (Losada, Montorio, Izal *et al.*, 2006). Although men reported experiencing significantly more dysfunctional thoughts, they reported experiencing significantly fewer depressive symptoms. One possible explanation for this apparently paradoxical result is that the relationship between gender, dysfunctional thoughts and symptoms of depression is mediated by another variable, such as rumination. Women have been found to use ruminative coping significantly more than men, and rumination has been shown to mediate the relationship between gender and depression (Grant *et al.*, 2004; Nolen-Hoeksema *et al.*, 1999). Although male caregivers report significantly higher levels of dysfunctional thoughts, it may be that they ruminate on these thoughts less than women and therefore report significantly lower levels of depressive symptoms than women.

5.3 Predictors of depression in dementia caregivers

The third part of this study aimed to evaluate the relative contributions of guilt, dysfunctional thoughts and cognitive fusion as predictors of caregiver depression. Of particular interest was how the content of cognition (thoughts, beliefs, attitudes) compares to the relationship one has with those cognitions (entangled versus defused) in their capacity to predict distress in dementia caregivers. Cognitive theory predicts that characteristic distortions and biases in thinking (i.e. dysfunctionality of content) should account for a significant portion of variance in depressive symptoms in dementia caregivers. Contextual behaviour therapies, such as Acceptance and Commitment Therapy (ACT), predict that the relationship one has with one's cognitions, the level of cognitive fusion, should account for a significant variance in distress in dementia caregivers.

Unfortunately, the DTACQ did not correlate with depression as predicted, preventing this variable from being tested as a predictor of caregiver depression as stated in the original analytic plan. The DAS, a measure of general dysfunctional attitudes which correlated significantly ($r = .25$, $p < .001$) with the DTACQ and with the CES-D ($r = .22$, $p < .01$) was used as a predictor in its place. The equivalence of the DAS and the DTACQ was considered at this point. Within CBT, dysfunctional attitudes such as perfectionism or dependency are thought to develop as a consequence of early learning and are hypothesised to predispose people to negative interpretations of life events (i.e. dysfunctional thoughts) (Beck *et al.*, 1979). Although entitled the Dysfunctional *Thoughts* About Caregiving Questionnaire, the DTACQ items can be seen as rigid or inappropriate rules for guiding one's behaviour (e.g. item 14 "to become a good caregiver would mean not making mistakes when taking care of a frail/sick relative"), which is the definition of a dysfunctional *attitude* within the CBT literature (Beck *et al.*, 1979). The two factors identified within the DTACQ, perception of sole responsibility and perfectionism can be understood as dysfunctional attitudes, indeed, perfectionism appears as a factor within measures of general dysfunctional attitudes (e.g. Common Beliefs Survey, Bassai, 1977; Dysfunctional Attitudes Scale, Weissman & Beck, 1978). Therefore the two measures were accepted as sufficiently similar for the DAS to be a valid measure to use in place of the DTACQ. Within the ACT model, dysfunctional thoughts and dysfunctional attitudes would not be differentiated and both would be seen as verbal behaviour. Therefore inclusion of the DAS within the regression model, rather than the DTACQ, still permits the comparison of a cognitive content based predictor with cognitive fusion. However, the inclusion of the DAS in place of the DTACQ prevents the utility of caregiving specific thoughts or attitudes being tested as a predictor of depressive symptoms in dementia caregivers.

Due to its established theoretical association with depression, guilt, as measured by the CGQ, was entered into the hierarchical regression first and it accounted for 36 per cent of variance in CES-D scores. The DAS was entered second, and did not

significantly predict variance in caregiver depression as measured by the CES-D, over and above the variance already accounted for by caregiver guilt. Cognitive fusion, as measured by the CFQ, was a significant predictor and accounted for a further 14 per cent of variance in caregiver depression, after variance accounted for by the CGQ. As the DAS did not account for additional variance in the model, the multiple regression analysis was repeated with only the CGQ and CFQ entered as predictors. Upon examination of the standardised beta values, cognitive fusion was a stronger predictor than caregiver guilt (.46 for cognitive fusion and .33 for caregiver guilt respectively). As a caregiver's score increased by one standard deviation on the CFQ, their score on the CES-D increased by 4.95 points, assuming that caregiver guilt is held constant. The strength of cognitive fusion as a predictor of depressive symptoms, in comparison to guilt as a predictor of depressive symptoms, is a notable finding, given the close association between guilt and depression, which is one of the diagnostic features of a depressive episode (American Psychiatric Association, 2000).

The finding that dysfunctional attitudes did not account for any variance in caregiver depression, beyond that accounted for by caregiver guilt, was unexpected. Dysfunctional attitudes have been found to correlate with depressive symptoms (e.g. Andrews *et al.*, 1993; Weissman & Beck, 1978) and to predict variance in depressive symptomatology (e.g. Kwon & Oei, 1992; Olinger *et al.*, 1987), as hypothesised by the cognitive model of depression. Although the sample mean for the CES-D was above the clinical cut-off for depression, this is not indicative of the presence of major depressive disorder. It is possible that the DAS did not account for significant variance in depressive symptoms because of restricted variance in depressive symptoms, that is, the sample was not sufficiently depressed for this relationship to be found.

As discussed in section 2.3, cognitive fusion is one of six processes within the ACT model of psychopathology. The model asserts that its opposite process, cognitive

defusion, contributes to greater psychological flexibility and wellbeing. Preliminary studies have found that decreases in the believability of thoughts (i.e. cognitive defusion) have been found to mediate reductions in symptoms in depression (Zettle *et al.*, 2011) and that the frequency of cognitive defusion behaviour has been found to be a significant predictor of reduction in tinnitus distress (Hesser *et al.*, 2009). The finding that cognitive fusion is a significant predictor of depressive symptoms in dementia caregivers supports the results of these preliminary studies. It also suggests that further research is warranted into the effectiveness of interventions that target the way in which an individual relates to their thoughts in reducing caregiver distress.

5.4 Study limitations

This study uses a cross-sectional design; therefore causation cannot be established for the main findings. Although correlations were found between caregiver guilt and depression, and dysfunctional thoughts about caregiving and dysfunctional attitudes, this does not imply that guilt causes depression in caregivers; the reverse may equally be true. Although both caregiver guilt, as measured by the CGQ, and cognitive fusion, as measured by the CFQ, were found to be significant predictors of variance in CES-D scores in dementia caregivers, again this does not imply a causal role for these variables. The cross-sectional nature of this study also prevented the evaluation of test-retest reliability of the CGQ and DTACQ in a UK sample of dementia caregivers.

In terms of recruitment, in order to achieve a clinically representative sample, several avenues of recruitment were pursued; contact was made with Alzheimer Scotland Dementia Cafes, the Fife Carers' Centre and the Scottish Dementia Clinical Research Network. Nonetheless, as is the case with many such studies, caregivers who are not in contact with voluntary or statutory agencies and who may well be the most distressed, are not represented here. It is an interesting challenge when studying caregiver distress that those who are most likely to feel the burden of caregiving are

also most likely to feel they do not have the time or emotional resilience to participate in research. The caregivers participating in this study, as with many other studies in this field, are most likely to be a subset of dementia caregivers, who may not be representative of caregivers in the general population, an issue which is frequently overlooked in this field. This does not negate the significance of the results of this study, yet the challenge remains for researchers in this field to actively seek out the most vulnerable and distressed caregivers. The initial recruitment strategy also included online recruitment through the Carers' UK Forum, but unfortunately the organisation did not respond to requests to use their forum for this purpose. Online recruitment may have contributed to the recruitment of a more diverse sample of caregivers, as more socially isolated caregivers or those who are not in contact with local services could have participated.

Unfortunately, due to the failure to find a significant correlation with depression, the DTACQ could not be used as a predictor variable in the regression analysis. Although a more general measure of dysfunctional attitudes was used instead, this prevented the direct comparison of the specific content of dysfunctional thoughts about caregiving with cognitive fusion as predictors of depression in dementia caregivers, which was one of the initial aims of this study.

Another limitation within this study was the challenge of finding appropriate measures to test convergent validity of the CGQ and DTACQ. As noted previously, caregiver guilt has not been extensively researched, and only one other measure of caregiver guilt could be found (Martin *et al.*, 2006). As this was developed with a small sample ($n = 70$) and without psychometric testing of its hypothesised structure, it was not felt that this was a sufficient 'gold standard' with which to compare the CGQ. Accordingly, the ZBI guilt factor, which was identified using psychometric procedures in a larger sample ($n = 152$) (Ankri *et al.*, 2005), was used. This also permitted direct comparisons between the British and Spanish samples, as this measure was used to establish convergent validity by the CGQ's authors (Losada *et*

al., 2010). No other measures of dysfunctional thoughts, specific to caregivers, were identified within the literature that could be used to test convergent validity. Consequently, measures of dysfunctional thoughts and attitudes from the wider psychological literature had to be considered, potentially introducing more error variance into the test of convergent validity.

The results of this study are also limited by the absence of measurement of some variables. As a measure of familism was not included, the hypothesised role of cultural variables in mediating differential responses between the British and Spanish caregivers could not be tested. The wider body of research literature provides some indications of differences in levels of familism; American white non-Hispanic caregivers have been found to have lower levels of familism than American Hispanic caregivers (Sabogal *et al.*, 1987) and British Caucasian caregivers have been found to have significantly lower levels of familism than British South Asian caregivers (Parveen & Morrison, 2009). However, no direct comparisons have been made of familism in British and Spanish caregivers. Data on ethnicity was not gathered in this study, which prevents the assessment of the possible role of ethnic background on responses within the British sample.

Another limitation of the study is the use of depression as the sole outcome measure and the exclusion of anxiety as an outcome measure. Anxiety has been neglected within the wider caregiving literature, although it is estimated to affect a quarter of caregivers (Cooper *et al.*, 2007). One systematic review (Schulz *et al.*, 1995) found seven articles examining the prevalence and correlates of caregiver anxiety, in comparison to 29 researching the prevalence and correlates of caregiver depression. In this study, it was decided that the inclusion of a measure of anxiety risked increasing the response burden on participants and reducing the response rate, thus jeopardising statistical power and the internal validity of the study. However, the associations between the CGQ and DTACQ and anxiety in British dementia caregivers remain to be explored.

5.5 Clinical and research implications

Several aspects of this study have direct relevance for clinical work with dementia caregivers. The CGQ has been demonstrated to be a valid measure for use with dementia caregivers and is likely to be of use in clinical work. Test-retest reliability and sensitivity to change has yet to be established for this measure in the UK; however, the CGQ may be a useful screening tool in an initial therapeutic assessment. The establishment of a clinical cut off also aids clinicians in determining the significance of a caregiver's score on the CGQ. As a whole scale, the DTACQ has also been shown to be valid, although a high score on this measure should not necessarily lead the clinician to assume the presence of depressive symptomatology. However, the DTACQ may provide a useful framework for discussions around the caregiver's expectations of themselves in this role, factors which prevent them from seeking help when necessary and their own self-care.

The association of cognitive fusion with depression in caregivers suggests that therapeutic interventions, which target the way in which an individual relates to their thoughts, may be an effective approach to use with dementia caregivers. This may include approaches such as ACT or mindfulness based CBT (MCBT, Teasdale *et al.*, 2000). Studies in other populations have also demonstrated that the way in which one relates to one's thoughts is significant; e.g. Teasdale *et al.* (2002) found that reduced metacognitive awareness, defined as when "negative thoughts/feelings are experienced as mental events, rather than as the self" (p.275), predicted relapse in residually depressed patients. There is conflicting evidence regarding whether or not treatment gains in CBT are mediated by altering dysfunctional thoughts and attitudes, with some studies providing support for this hypothesis (Casey *et al.*, 2005; DeRubeis *et al.*, 1990; Hofmann, 2004) and others contradicting it (Burns & Spangler, 2001; Dimidjian *et al.*, 2006; Jacobson *et al.*, 1996). In the debate concerning the similarities and differences between ACT and CBT, some authors (e.g. Arch & Craske, 2008) have argued that CBT includes cognitive distancing,

which performs the same function as cognitive defusion within ACT. Indeed, a recent session by session comparison of mechanisms of change in CBT and ACT (Forman *et al.*, 2012) found that cognitive defusion was a mediator of change across both conditions. Given the current conflicting evidence, in answering calls for mechanisms of change to be tested within dementia caregiver interventions (Zarit & Femia, 2008), it would be beneficial for researchers to test the role of cognitive fusion as a mediator of treatment gain with dementia caregivers in both CBT and ACT therapy programmes.

The refinement of the CGQ and DTACQ also presents avenues for future research. As noted earlier, Factor 5 of the CGQ has only 2 items loading onto it, which is not adequate for a well-defined factor. Whilst this does not detract from the use of the CGQ as a whole measure, it may benefit from a re-examination of guilt about neglecting other relatives, and extending this factor to include items about neglecting other key relationships and roles, such as friends or employment. Factor 2 of the DTACQ would benefit from revision, both to increase the number of items loading onto it, in order to achieve a well-defined factor, and to better capture different aspects of perfectionism in relation to caregiving. Both measures would also benefit from the establishment of test-retest reliability and sensitivity to change post-intervention in an English speaking population.

It may also be useful to test the relationships between the CGQ and the DTACQ and other constructs relevant to caregiver well-being. Anxiety, as discussed previously may be one such outcome. In addition, the five factor structure of the CGQ suggests that it is helpful to think about caregiver guilt as a multidimensional construct, which may influence a variety of behaviours, for example reducing social contact or reducing leisure time. These associations were examined in the Spanish development study (Losada *et al.*, 2010); however, this has not yet been tested with a longitudinal design, to establish causal relationships. The role of dysfunctional thoughts in relationship to other variables such as familism, role strain and self-care

has also not yet been tested in an English speaking population, and a longitudinal design would improve current understanding of the direct or indirect effects of dysfunctional thoughts on depressive symptoms.

5.6 Summary and conclusions

This thesis comprises a three part study aimed at contributing to the literature concerning outcome measures for interventions targeting dementia caregivers and the development of the ACT model with new populations. All three parts use data from a cross-sectional quantitative survey of dementia caregivers. Part 1 concerns the psychometric properties of the Caregiver Guilt Questionnaire (CGQ), Part 2 focuses on the psychometric properties of the Dysfunctional Thoughts About Caregiving Questionnaire (DTACQ) and Part 3 concerns the relationships between the content of cognition and the relationship one has to cognition and depression in dementia caregivers.

In Part 1, principal axis factoring was used to explore the factor structure of the CGQ. A five factor structure was found, replicating that found in the initial development of the measure in Spain (Losada *et al.*, 2010). The factors were labelled ‘guilt over own actions’ (Factor 1), ‘guilt over perceived inadequacies as a caregiver’ (Factor 2), ‘guilt over experience of negative emotions in relation to caregiving’ (Factor 3), ‘guilt about attending to own needs’ (Factor 4) and ‘guilt about neglecting other relatives’ (Factor 5). The internal consistencies of the whole scale and its five factors were all adequate. A ROC analysis was also completed and a clinical cut-off of 22 was established to balance sensitivity and specificity of the measure in predicting a score in the clinical range on an epidemiological measure of depression. Convergent validity was established for this measure.

In Part 2, the factor structure of the DTACQ was explored using principal axis factoring. A two factor structure was identified, replicating that found in the Spanish

development study (Montorio *et al.*, 2009). One item was removed due to its poor psychometric properties. Factor 1 was labelled ‘perception of sole responsibility’ and Factor 2 ‘perfectionism’. The internal consistency of the whole scale and Factor 1 was adequate; however, that of Factor 2 was not. Convergent validity was established for this measure; however, no significant relationship was found between the DTACQ and the caregiver depression, as expected.

In Part 3, caregiver guilt, dysfunctional attitudes and cognitive fusion were entered into a hierarchical regression model. Dysfunctional attitudes did not significantly predict variance in caregiver depression, over and above the variance already accounted for by caregiver guilt. Both caregiver guilt and cognitive fusion were significant predictors; however, cognitive fusion was a stronger predictor of caregiver depression than guilt.

The current results suggest that the Caregiver Guilt Questionnaire is a psychometrically robust and valid measure for use with British dementia caregivers, and is a significant predictor of caregiver depression. Whilst the factor structure for the Dysfunctional Thoughts About Caregiving Questionnaire was replicated, items loading onto Factor 2, perfectionism, would benefit from further development to improve the internal consistency. The lack of a significant relationship between the DTACQ and caregiver depression may be explained by the presence of ‘third variables’ not measured within this study, such as role strain, or cultural factors such as familism, which should be explored in further research. The failure of dysfunctional attitudes to predict caregiver depression was unexpected; this may be a result of the community sample used, rather than a sample of caregivers diagnosed with major depressive disorder. The strength of cognitive fusion as a predictor of caregiver depression is consistent with contextual CBT models of psychopathology, such as ACT, and suggests that the way in which individuals relate to their thoughts and feelings should be measured as a potential mechanism of change in dementia caregiver interventions.

6 Journal Article

Title: Validation of the Caregiver Guilt Questionnaire (CGQ) in a sample of British dementia caregivers

Running Title: Validation of the Caregiver Guilt Questionnaire

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ABSTRACT

Background: Depression is well documented as a key outcome variable for dementia caregivers however guilt has been under-researched, which may be in part due to the lack of an appropriate measure. The Caregiver Guilt Questionnaire (CGQ) was originally developed and piloted with a Spanish population but has not yet been tested in an English-speaking population.

Methods: A cross-sectional postal survey was undertaken with a sample of 221 dementia caregivers in the UK, as part of a larger study of dementia caregiver outcome measures.

Results: The five factor structure identified for the CGQ in the Spanish sample was replicated in this study. The five factors, 'guilt about doing wrong by the care recipient', 'guilt about failing to meet the challenges of caregiving', 'guilt over experience of negative emotions in relation to caregiving', 'guilt about self-care' and 'guilt about neglecting other relatives' accounted for 60 per cent of the variance. Internal consistencies for the whole scale and factors were acceptable, and convergent validity was established with the Zarit Burden Interview guilt factor. A higher score on the CGQ was associated with a higher score on the Center for Epidemiologic Studies Depression scale (CES-D) and a new cut off score of 22 was established, which predicted a clinical score on the CES-D with 80.0 per cent sensitivity and 61.5 per cent specificity.

Conclusions: The replication of the five factor structure suggests that these are universal themes within the feelings of guilt experienced by dementia caregivers, irrespective of cultural context. The CGQ has been demonstrated to be a valid measure for use with British dementia caregivers and is likely to be of use in clinical and research settings.

Key words: guilt, depression, caregiver, carer, dementia, psychometrics, outcome

INTRODUCTION

It is well established that caring for a family member with dementia can have a significant negative impact on the caregiver. As well as having social and financial implications, caregivers suffer higher levels of depression and anxiety, greater incidence of physical health problems and a shortened life expectancy (Schulz *et al.*, 2005). Outcomes such as depression and caregiver burden are well researched, however some emotions, such as guilt, have been relatively neglected. Guilt has been shown to be associated with depression in the general population (Kim *et al.*, 2011) and is a common experience of caregivers (Rosa *et al.*, 2010; Samuelsson *et al.*, 2001); Gonyea *et al.* (2008) found that 65 per cent of their sample of adult-child caregivers experienced guilt in relation to their caregiving role. Zarit and Femia (2008) highlight that although depression is prevalent in dementia caregivers, it is not universal; typically 50 – 80 per cent of samples do not show clinically significant symptoms of depression. Research into emotions frequently experienced by caregivers, such as guilt, will further inform clinical interventions where depression may not always be an appropriate outcome. However although guilt is a common experience of caregivers, without a psychometrically robust measure with a clinical cut off, it is difficult to measure and ascertain what level of guilt is likely to be dysfunctional.

Martin *et al.* (2006) designed a caregiving shame and guilt scale, with six items pertaining to caregiver guilt, although subscales were not identified through factor analysis. In a sample of 70 dementia caregivers, Martin *et al.* (2006) found guilt was not associated with depression in caregivers, a surprising finding given that guilt is associated with depression in the general population (Kim *et al.*, 2011). However this finding may be confounded by correlating current depressive symptomatology, (measured by the Centre for Epidemiological Studies Depression Scale [CES-D: Radloff, 1977]), with hypothetical situations which may induce feelings of guilt. Statements were conditionally phrased and worded in terms of how the caregivers would feel if they acted in a certain manner in relation to caregiving behaviors. An alternative guilt scale was identified by Ankri *et al.* (2005) in a factor analysis of the

Zarit Burden Interview (ZBI) (Zarit *et al.*, 1980). Ankri *et al.* (2005) identified a four item guilt factor, which was found to be associated with depression. Given that current models of guilt (e.g. Tangney & Dearing, 2002) suggest that the object of negative evaluation in guilt is thought to be specific behaviors, it is likely that a four item (Ankri *et al.*, 2005) or six item (Martin *et al.*, 2006) scale will not measure all relevant caregiving behaviors which may relate to caregiver guilt. In addition, neither scale yields a clinical cut off that indicates a level of guilt which is likely to be dysfunctional.

The Caregiver Guilt Questionnaire (CGQ) (Losada *et al.*, 2010), a 22 item self-report measure, was developed to address the shortcomings of existing measures. A large number of items were tested and reduced using factor analysis, in order to develop a measure of caregiver guilt which encompasses a wide range of caregiving behaviors relevant to the experience of guilt in a psychometrically robust manner. In a sample of 288 Spanish dementia caregivers, a principal components analysis identified a five factor structure, which explained 59.3 per cent of the variance. Convergent validity was established with the ZBI guilt factor and internal consistencies for the whole scale and five subscales were found to be adequate to good (Cronbach's α 0.61 – 0.89). Although the CGQ was found to be associated with depression, in the absence of a cut off it is difficult to ascertain what level of guilt is likely to be clinically significant. While the CGQ was published in English, its psychometric properties have not been evaluated with an English-speaking population. The aim of this study is to test the psychometric properties of the CGQ in a sample of British dementia caregivers and to establish a clinical cut off.

METHODS

Sample

Participants were informal caregivers of persons with dementia and were recruited as part of a larger project investigating outcome measures for dementia caregivers.

Participants were included if they were 18 years or older, spoke English as a first language, identified themselves as the primary unpaid caregiver for the person with dementia, and the person with dementia lived in the community. Caregivers were recruited through a postal survey sent to caregivers enrolled on the Scottish Dementia Clinical Research Network (SDCRN) research register, advertisements placed in a local Carers' Centre newsletter and presentations given at local Alzheimer Scotland caregiver meetings. A three month reminder pack was sent to caregivers on the SDCRN research register if they had not responded to the initial mailing. 593 questionnaire packs were sent out to SDCRN registrants and 226 were returned, a response rate of 40.3 per cent. A further 13 responses were received from the other recruitment sources, giving 239 total responses. 11 responses were excluded as the participants did not meet inclusion criteria and a further seven were excluded due to whole scales being left incomplete. Characteristics of the final sample ($n = 221$) and the sample from the Spanish development study (Losada *et al.*, 2010) are shown in Table 1.

 Insert Table 1 about here

Measures

Demographic characteristics: The following demographic characteristics were assessed: age, sex, and education level of the caregiver, relationship to the person with dementia and living arrangements. The caregivers were asked about length of the caring relationship, average time spent caring each day and whether the caregiver receives help from others. Additionally, the age and sex of the person with dementia, and dementia diagnosis were also assessed.

Caregiver Guilt Questionnaire (CGQ: Losada *et al.*, 2010): This is a 22 item self-report measure. Participants rate how frequently they have experienced specified thoughts or feelings of guilt over the past two weeks. Sample items include "I have felt bad about getting angry with the person I'm caring for" and "I have felt bad for leaving my relative in the care of someone else while I had fun". In a sample of 288

Spanish dementia caregivers, the scale was shown to have good internal consistency (Cronbach's $\alpha = 0.88$ for the total scale).

Zarit Burden Inventory guilt factor (ZBI: Zarit et al., 1980): The four-item guilt factor from the ZBI identified by Ankri et al. (2005) was chosen for use as a measure of convergent validity in this study. This subscale produces a score between 0 and 16, where a higher score indicates a greater level of guilt. The use of this scale for convergent validity also permits comparisons between data obtained from this study and the original development study of the CGQ (Losada et al., 2010).

Centre for Epidemiological Studies – Depression (CES-D: Radloff, 1977): This is a widely used self-report measure assessing depressive symptomatology in community samples. The scale contains 20 items, and produces a score between 0 and 60, where a higher score indicates higher levels of depressive symptoms. A score of 16 or greater is used as the cut off to indicate high levels of depressive symptoms. In the initial validation study (Radloff, 1977), internal consistency was found to be high (alpha coefficient of at least 0.84 across the four samples), the scale discriminated between clinical and non-clinical samples, and showed moderate correlations with other measures of depression. The CES-D has been shown to perform as a moderately accurate screening tool for major depressive disorder in an older adult population (Haringsma et al., 2004).

Statistical Power

Numerous rules of thumb exist regarding statistical power and sample size for exploratory factor analysis. Considering the ratio of subjects (N) to items being analyzed (p) Gorsuch (1983) recommends a minimum $N:p$ ratio of 5:1; Everitt (1975) recommends at least 10:1. A Monte Carlo study by MacCallum et al. (1999) suggested that sample sizes as low as 60 cases can be adequate if the communalities are consistently high (all greater than .6). With communalities in the .5 range, well

determined factors are required and a larger sample size ($n = 100-200$) in order to achieve a good recovery of population factors. The final sample size meets all three criteria.

RESULTS

There was a low level of missing data in this study; across the CGQ, ZBI guilt factor and CES-D items, 1.5 per cent of responses were missing. Expectation maximization was used to impute missing data. Means and standard deviations for key variables are shown in Table 2.

Insert Table 2 about here

Factor structure of the CGQ

Principal axis factoring was used to analyze the factor structure of the CGQ. The scree plot, parallel analysis (conducted using 1000 permutations of the original dataset) and Velicer's MAP test all indicated that five factors should be extracted. The unrotated solution explained 60 per cent of the variance. A Promax oblique rotation was completed, as it was anticipated that the factors would correlate, which they did ($r = .36 - .67$). Factor loadings are shown in Table 3.

Insert Table 3 about here

The factors were interpreted as 'guilt about doing wrong by the care recipient' (Factor 1), 'guilt about failing to meet the challenges of caregiving' (Factor 2), 'guilt over experience of negative emotions in relation to caregiving' (Factor 3), 'guilt about self-care' (Factor 4) and 'guilt about neglecting other relatives' (Factor 5). Twenty-one of the 22 items loaded on the same factors in this study as in the Spanish development study; the exception was item 20 (I have felt guilty about having so

many negative emotions in relation to caring). This item loaded on Factor 1 (guilt about doing wrong by the care recipient) in the Spanish sample and loaded on Factor 3 in the in present study. All factors share the same labels in the British and Spanish study, with the exception of Factor 3 of the current study, where the inclusion of item 20 altered the interpretation. The third, fourth and fifth factors extracted in this sample were extracted in a different order in the Spanish sample (Losada *et al.*, 2010). Factor 3 in this study (guilt over experience of negative emotions in relation to caregiving) was extracted as the fifth factor in the Spanish study; Factor 4 in this study (guilt about self-care) was extracted as the third factor in the Spanish study; and Factor 5 in this study (guilt about neglecting other relatives) was extracted as the fourth factor in the Spanish study. Overall, however, the five-factor structure originally reported by Losada *et al.* (2010) is replicated in the current sample.

Internal consistency

Internal consistencies, as measured by Cronbach's alpha, for both the UK and Spanish sample are shown in Table 4. The internal consistencies of the whole scale and all five factors within the British sample are good to excellent.

 Insert Table 4 about here

Clinical cut off

In the initial development study of the CGQ (Losada *et al.*, 2010), a clinical cut off score was not reported. A receiver operating characteristics (ROC) analysis was conducted to analyze the association between the CGQ and the presence of a score on the CES-D above the clinical cut off. The area under the curve (AUC) found with ROC analysis was .79 (SE=0.03; 95 per cent confidence intervals [CI] .726-.844; $p<.001$). With a clinical score on the CES-D as the criterion, the cut off score of 22 on the CGQ showed the optimal balance between sensitivity (80 per cent) and specificity (61.5 per cent), with a positive predictive value (PPV) of 70.2 per cent.

Convergent validity

Convergent validity was assessed by correlational analysis with the guilt factor of the ZBI. In order to control for the risk of increasing the Type I error rate by performing multiple post-hoc tests, the Bonferroni correction was applied for the two correlations undertaken, which reduced the acceptable p level to .025. The CGQ total score and the ZBI guilt factor correlated positively and significantly ($r = .653$, $p < .001$), indicating that caregivers with a high CGQ total score also had a high ZBI guilt factor score. Each factor of the CGQ also correlated positively and significantly with the ZBI guilt factor, as shown in Table 5.

 Insert Table 5 about here

Associations between caregiver guilt and demographic characteristics

Associations between demographic characteristics and the CGQ were examined using independent sample t tests. In order to control for the risk of increasing the Type I error rate by performing multiple post-hoc comparisons, the Bonferroni correction was applied for the two t tests completed, which reduced the acceptable p level to .025. Levene's test was used to assess homogeneity of variance and where this assumption was not met automatic statistical adjustment was made for the heterogeneity of variance. Means and standard deviations are shown in Table 2. Adult-child caregivers experienced significantly higher levels of guilt, as measured by the CGQ total score, ($t(213) = 2.334$, $p < .025$) in comparison to spousal caregivers. The effect size was small to medium ($d = 0.41$). Means and standard deviations are shown in Table 2. Female caregivers experienced significantly higher levels of guilt, as measured by the CGQ total score, than male caregivers ($t(197.30) = 3.639$, $p < .001$). The effect size was small to medium ($d = 0.46$).

DISCUSSION

Psychometric properties of CGQ

The CGQ (Losada *et al.*, 2010) was designed to measure feelings of guilt experienced by dementia caregivers. The initial development study found that the CGQ measured multiple facets of guilt; the five factor structure found in the Spanish sample (Losada *et al.*, 2010) was replicated in this study. All CGQ factors intercorrelated in the British sample, as expected for different facets of an emotion. However, variations in the strength of correlations between factors suggest that the factors do measure discernibly different aspects of guilt.

This study also sought to establish a clinical cut-off for the CGQ, which the initial development study did not do. In order to ascertain whether the level of guilt a caregiver experiences is likely to be associated with clinically significant symptoms and for the measure to be most useful to clinicians, a clinical cut off is essential. ROC analyses indicated that the optimal cut off was 22, to balance specificity and sensitivity (80 per cent and 61.5 per cent respectively). Caregivers scoring 22 or above on the CGQ are likely to show clinical levels of depressive symptomatology (as measured by the CES-D). This cut off is relatively low in comparison to the possible total score of 88. Higher cut offs were considered, however this quickly reduced the sensitivity of the measure. On examination of the data distribution, a slight positive skew is evident in caregivers' responses. Caregivers did not use the full range of the scale and endorse the highest possible levels of guilt. Even though the caregivers in this sample had a higher mean score for guilt than in the Spanish sample (27.61 [14.10] c.f. 17.90 [12.70]), this was still low in comparison to the level of emotionality which could have been endorsed.

It is important to note that the measure of depression used was an epidemiological measure, rather than a clinical diagnostic tool, therefore a score above the cut-off on the CGQ does not necessarily indicate the presence of a major depressive episode,

but highlights a potentially treatable pattern of maladaptive cognition, emotion and behavior, which may be associated with depression. As highlighted by Zarit and Femia (2008), 50 – 80 per cent of caregiving samples do not show clinically significant symptoms of depression; however, guilt is a common experience of caregivers (Gonyea *et al.*, 2008; Rosa *et al.*, 2010; Samuelsson *et al.*, 2001) and may have an impact on self-care and use of social support (Losada *et al.*, 2010). Longitudinal studies are required to establish causation and mediation; however, early interventions targeting caregiver guilt and its associated maladaptive cognitions and behaviors may lead to improvements in caregivers' psychological wellbeing before the development of a major depressive episode.

Individual CGQ items loaded onto the same factors in the British and Spanish samples, with the exception of item 20 (I have felt guilty about having so many negative emotions in relation to caring). In the Spanish sample, this loaded most strongly onto Factor 1 'guilt about doing wrong by care recipient' however it also cross-loaded onto Factor 2 'guilt about failing to meet the challenges of caregiving'. In the British sample, it loaded on Factor 3 'guilt about experience of negative emotions in relation to caregiving', with which it appears to have greater face validity. Although the original Spanish scale was translated into English and back-translated, it is possible that this item may have different nuances in English and Spanish.

The replication of the factor structure across the two samples suggests that these are universal themes within the feelings of guilt experienced by dementia caregivers, irrespective of cultural context. British caregivers endorsed higher levels of guilt than Spanish caregivers (27.61 (14.10) c.f. 17.90 (12.70)). This may be as a result of cultural differences or the methodology employed. Losada *et al.* (2010) used face to face interviews for completion of the CGQ; Spanish caregivers may have been less willing to acknowledge feelings of guilt over their actions or emotions to another person, whereas British caregivers may have acknowledged the presence of feelings

of guilt more easily due to the anonymity of a postal study. The higher levels of guilt endorsed by British caregivers suggests that clinicians should be particularly sensitive to the experience of guilt in caregivers and the impact that this may have on the caregiver's self-care, use of support services and expectations of themselves.

The five factors of the CGQ highlight the different levels at which caregivers experience guilt: in relation to their behaviors, in relation to their appraisal of their actions, and in relation to their emotional experience. This gives an indication of the ways in which feelings of guilt may be alleviated in caregivers; through caregiver training programs (in order to learn the most effective caregiving strategies and techniques), cognitive behavioral therapy (in order to examine the realism and utility of caregiving appraisals) and peer support (in order to normalize the strong emotions that are often experienced by caregivers). The excellent internal consistency suggests that both the whole scale and subscales are likely to be useful to monitor changes in levels and types of guilt following clinical intervention, although test-retest reliability has yet to be established.

Factor 5 'guilt about neglecting other relatives' only has two items loading on it in the British sample. This was also found in the Spanish development study (Losada *et al.*, 2010). This aspect of guilt is conceptually different to the other four factors, as it relates to the caregivers' role in the wider family system rather than to the caregiver's behavior in relation to the person with dementia. This factor contributes significantly to the total variance accounted for by the factor model; however, with only two items it is not a well-defined factor. In order to develop this into a well defined factor, further items should be investigated for inclusion, for example guilt about neglecting other significant relationships out with the family, such as friends or colleagues.

The internal consistency of the CGQ scale and its five factors in the UK sample are all good. With the exception of Factor 4, all of the Cronbach's alphas are equal or superior to those found in the Spanish development study (Losada *et al.*, 2010). Based on the alpha values, this suggests that the total scale and subscales are reliable. Convergent validity was established; caregivers reporting higher levels of guilt on the CGQ also reported higher levels of guilt on the ZBI guilt factor and higher levels of depressive symptomatology on the CES-D. These results do not give an indication of causality; higher levels of guilt could be a consequence of depression as well as a precursor to it.

As well as the relative neglect of caregiver guilt in the research literature, variables associated with caregiver guilt have also been under researched. British female caregivers, irrespective of their relationship to the care recipient, reported higher levels of guilt than male caregivers. Losada *et al.* (2010) also found that female caregivers reported higher levels of guilt than male caregivers on the CGQ. Gender differences in psychological outcomes for caregivers have been attributed to differences in caregiving norms, that there is a stronger norm for caregiving and nurturing for women (Raschick & Ingersoll-Dayton, 2004). This may explain higher levels of self-reported guilt in female caregivers if they perceive that they have transgressed these norms.

Adult-child caregivers reported higher levels of guilt on the CGQ than spousal caregivers, which is consistent with other studies in this field (e.g. Ankri *et al.*, 2005; Losada *et al.*, 2010) in other cultures. This finding is commonly attributed to adult-child caregivers being more likely to live separately from the care recipient, as well as a greater likelihood of role strain due to a greater number of competing demands (e.g. employment, caring for young children) (Yee & Schulz, 2000).

Comparison of British and Spanish samples

This study was a cross-cultural validation of the Caregiver Guilt Questionnaire. Several key differences between the British and Spanish samples should be noted. There was a greater proportion of spousal caregivers in the UK sample in comparison to the Spanish samples (80.5 per cent cf. 37.2 per cent). Bond *et al.* (1999) conducted a large scale survey (n = 1127) of informal caregivers of physically or mentally frail older people in England. Of all the older people who identified a key informal caregiver (n = 884), the caregiver was most commonly a spouse (39 per cent) or an adult-child (39 per cent). This suggests that spousal caregivers are relatively over-represented in this study in comparison to caregivers in the general population in the UK. A recent meta-analysis (Pinquart & Sorensen, 2011) found that spousal caregivers reported significantly higher levels of depressive symptomatology than adult children; however, despite the differences in demographic characteristics, the mean depression score was very similar across the British and Spanish samples.

The British sample contained substantially more male caregivers than the Spanish sample (34.4 per cent cf. 20.8 per cent), however this is consistent with the proportion of male caregivers found by Bond *et al.* (1999) in their UK wide survey. Greater inclusion of male caregivers may be a result of recruitment methods; Losada *et al.* (2010) recruited from local health and social care centers, whereas caregivers in the current study were principally recruited from a research register. Research has shown that men show less help-seeking behavior than women (Galdas *et al.*, 2005) therefore a strategy which seeks to recruit caregivers through the services that they receive, as used by Losada *et al.* (2010) is less likely to recruit large numbers of men. This study recruited through a research register which is not dependent on service use, which may explain the greater proportion of male caregivers in this sample. Pinquart and Sorensen (2011) also found that spousal caregivers are more likely to be male therefore the higher number of spousal caregivers in this sample may also explain the greater number of male caregivers.

Future research and study limitations

The refinement of the CGQ presents avenues for further research; as noted earlier Factor 5 may benefit from inclusion of further items in order to create a well-defined factor. The test-retest reliability and sensitivity to change post-intervention of the CGQ has not been established with British caregivers, or its relationship with other key outcome variables, such as anxiety or placement of care recipients in care homes. The five factor structure of the CGQ suggests that it is helpful to think about caregiver guilt as a multidimensional construct, which may influence a variety of behaviors, for example reducing social contact or reducing leisure time. These associations were examined in the Spanish development study (Losada *et al.*, 2010) however this has not yet been tested with a longitudinal design in order to establish causal relationships.

In order to achieve a clinically representative sample several avenues of recruitment were pursued. Nonetheless as is the case with many such studies, caregivers who are not in contact with voluntary or statutory agencies and who may well be the most distressed, may not be represented here. It is interesting to reflect on recruitment of participants into studies examining the experience of caregiving. Those individuals who may feel the most acute challenges of caregiving may also be more likely to feel they do not have the time or emotional resilience to participate in research. Thus, as with most other studies, caregivers participating in this study may represent a subset of dementia caregivers; an issue that is frequently overlooked in this field. This does not negate the significance of the results of this study, yet the challenge remains for researchers in this field to actively seek out the most vulnerable and distressed caregivers.

Conclusion

The CGQ has been demonstrated to be a valid measure for use with dementia caregivers and is likely to be of use in clinical and research work. Test-retest

reliability and sensitivity to change has yet to be established for this measure in the UK, however the CGQ may be a useful screening tool in an initial therapeutic assessment. The establishment of a clinical cut off will also help clinicians to determine the significance of a caregiver's score on the CGQ and identify potentially treatable patterns of maladaptive cognition, emotion and behavior.

Conflict of Interest

None.

Description of authors' roles

LR designed the study, collected and analysed the data, and wrote the paper. KL and DG supervised the design of the study and the data analysis and contributed to writing the paper. KQ supervised the data collection and contributed to the writing of the paper.

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FIGURES/TABLES

Table 1: Sample characteristics for British and Spanish samples

| | | % | <i>M</i> | <i>SD</i> |
|--------------------------------------|----------------------|-------------|----------|-----------|
| Caregiver age (years) | Roach <i>et al.</i> | | 68.6 | 11.5 |
| | Losada <i>et al.</i> | | 59.6 | 12.6 |
| Female caregivers | Roach <i>et al.</i> | 65.6 | | |
| | Losada <i>et al.</i> | 79.2 | | |
| Years education | Roach <i>et al.</i> | | 13.4 | 3.5 |
| | Losada <i>et al.</i> | | NR | NR |
| Spousal caregivers | Roach <i>et al.</i> | 80.5 | | |
| | Losada <i>et al.</i> | 37.2 | | |
| Adult-child caregivers | Roach <i>et al.</i> | 17.3 | | |
| | Losada <i>et al.</i> | 57.6 | | |
| Living with care recipient | Roach <i>et al.</i> | 88.0 | | |
| | Losada <i>et al.</i> | 78.1 | | |
| Alzheimer's disease : other dementia | Roach <i>et al.</i> | 51.4 : 34.5 | | |
| | Losada <i>et al.</i> | 58.4 : 41.6 | | |
| Care recipient age (years) | Roach <i>et al.</i> | | 76.0 | 8.2 |
| | Losada <i>et al.</i> | | 79.0 | 8.4 |
| Daily hours caring | Roach <i>et al.</i> | | 14.6* | 8.4 |
| | Losada <i>et al.</i> | | 10.9 | 7.8 |
| Duration of caring | Roach <i>et al.</i> | | 4.1 | 3.5 |
| | Losada <i>et al.</i> | | 4.4 | 3.8 |

* This mean was calculated using all available data. Some caregivers (n=57) reported spending 24 hours caring each day. This was accepted as the subjective experience of caregiving was felt to be most important in this study. If caregivers who reported caring 24 hours each day are removed, the mean daily hours caring becomes 9.6 hours.

Table 2: Means and standard deviations for all variables in the whole sample and across relevant groups

| | Caregiver gender | | Caregiver relationship | | Residence | | Overall sample |
|------------------|------------------|------------------|------------------------|------------------|---------------------------|------------------|------------------|
| | Male | Female | Spousal | Adult-child | Lives with care recipient | Lives separately | |
| CES-D | 14.76 (8.49) | 20.96 (11.21) | 18.21 (10.25) | 21.68 (12.52) | 18.95 (10.61) | 18.70 (12.31) | 18.83 (10.75) |
| CGQ | 23.39 (10.91) | 29.83 (15.08) | 26.58 (13.61) | 32.43 (15.81) | 27.13 (13.74) | 31.41 (16.62) | 27.61 (14.10) |
| ZBI guilt factor | 5.29 (2.61) | 5.72 (3.17) | 5.36 (2.96) | 6.45 (2.99) | 5.51 (3.04) | 6.04 (2.65) | 5.57 (2.99) |

Table 3: Factor loadings with oblique rotation of CGQ items

| CGQ Item | Factor | | | | |
|---|-------------|------------|------|-----|---|
| | 1 | 2 | 3 | 4 | 5 |
| 2. I have felt guilty about the way I've sometimes behaved with my relative. | .81 | | | | |
| 8. I have felt bad about things I may have done wrong with the person I'm caring for. | .58 | | | | |
| 10. I have felt bad about getting angry with the person I'm caring for. | 1.14 | -.30 | | | |
| 11. I have felt bad about telling off the person I'm caring for, for some reason. | .88 | | | | |
| 12. I've got angry with myself for having negative feelings towards the person I'm caring for. | .40 | | | | |
| 14. I have felt bad about not having more patience with the person I'm caring for. | .71 | | | | |
| 5. I have thought that I'm not doing things right with the person I'm caring for. | .30 | .46 | | | |
| 6. I have thought that, given the circumstances, I'm doing a good job as a caregiver. | | .40 | | | |
| 9. I have thought that perhaps I'm not caring well for my relative. | | .65 | | | |
| 13. I've found myself thinking that I'm not up to the job. | | .60 | | | |
| 21. I have thought that the way I care for my relative may not be appropriate and may make his/her problem get worse. | | .86 | | | |
| 22. I have felt guilty thinking that my lack of information and preparedness might mean that I'm not handling the care of my relative in the best way possible. | | .85 | | | |
| 17. I have felt guilty about having wished that others "could have this burden" or suffer as I do. | | | .53 | | |
| 18. I have felt like a bad person for hating and/or envying other relatives who could have taken responsibility for some caring and do not do so. | | | 1.02 | | |
| 19. I have felt bad for having negative feelings (e.g. hate, anger or resentment) towards some relatives. | | | .91 | | |
| 20. I have felt guilty about having so many negative emotions in relation to caring. | | | .37 | | |
| 1. I have felt bad about having made some plans or done activities without taking my | | | | .32 | |

| | | | | | | | | |
|---|--------------------------|-------|-------|------|------|------|--|--|
| relative into account. | | | | | | | | |
| 7. When I've gone out to do a pleasant activity (e.g. eating out in a restaurant) I've felt guilty and unable to stop thinking that I should be caring for my relative. | | .58 | | | | | | |
| 15. I have felt bad about leaving my relative in the care of someone else while I do my own things (e.g. work, shopping, going to the doctor). | | .80 | | | | | | |
| 16. I have felt bad for leaving my relative in the care of someone else while I had fun. | | 1.01 | | | | | | |
| 3. I have felt bad for not looking after my other relatives (husband, wife, children...) as I should, due to my caregiving. | | 1.04 | | | | | | |
| 4. I have felt bad about not being able to devote more time to my family (husband, wife, children...) due to my caregiving. | | .95 | | | | | | |
| Unrotated solution | Sums of squared loadings | 8.54 | 2.43 | 1.12 | 0.96 | 0.81 | | |
| | % variance explained | 38.83 | 11.02 | 2.10 | 4.36 | 3.69 | | |
| Rotated solution | Sums of squared loadings | 6.43 | 6.65 | 5.52 | 5.96 | 4.79 | | |

NB: Loadings <.3 are not shown. Where an item loads on two factors >.3, the loading in bold is the factor to which the item is allocated. Factor loadings > 1 are a result of oblique rotation.

Table 4: Internal consistencies for CGQ in the British and Spanish sample

| Current study | Cronbach's alpha | Losada <i>et al.</i> (2010) | Cronbach's alpha |
|---------------|------------------|-----------------------------|------------------|
| Factor 1 | .90 | Factor 1 | .89 |
| Factor 2 | .80 | Factor 2 | .76 |
| Factor 3 | .85 | Factor 5 | .61 |
| Factor 4 | .84 | Factor 3 | .69 |
| Factor 5 | .94 | Factor 4 | .86 |
| Whole scale | .93 | Whole scale | .88 |

NB: Due to the differences in the order of extraction between the British and Spanish samples, factors are listed in different orders to permit a direct comparison of internal consistencies of the same subscales.

Table 5: Correlations between ZBI guilt factor and CGQ factors

| | 1 | 2 | 3 | 4 | 5 | 6 |
|---------------------|------|------|------|------|------|---|
| 1) CGQ Factor 1 | - | | | | | |
| 2) CGQ Factor 2 | .67* | - | | | | |
| 3) CGQ Factor 3 | .37* | .51* | - | | | |
| 4) CGQ Factor 4 | .50* | .60* | .58* | - | | |
| 5) CGQ Factor 5 | .36* | .50* | .52* | .59* | - | |
| 6) ZBI guilt factor | .43* | .57* | .53* | .52* | .49* | - |

* $p < .001$

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Appendix 1 – Author guidelines for Clinical Psychology and Psychotherapy

Clinical Psychology & Psychotherapy

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MANUSCRIPT STYLE

The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
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- All articles should include a **Key Practitioner Message** — 3-5 bullet points summarizing the relevance of the article to practice.
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Research Articles: Substantial articles making a significant theoretical or empirical contribution.

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Assessments: Articles reporting useful information and data about new or existing measures.

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Book Reviews: Published on invitation only. Critical summaries of recent books that are of general interest to readers of the journal.

Reference style . The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

A. A typical citation of an entire work consists of the author's name and the year of publication .

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

B. If the author is named in the text, only the year is cited .

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary .

Example: In a 1989 article, Gould explains Darwin's most successful. . .

D. Specific citations of pages or chapters follow the year .

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

E. When the reference is to a work by two authors, cite both names each time the reference appears .

Example: Sexual-selection theory often has been used to explore patters of various insect matings (Alcock&Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* . (meaning "and others") .

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al.*, 1997) When the reference is to a work by six or more authors, use only the first author's name followed by *et al.* in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

G. When the reference is to a work by a corporate author, use the name of the organization as the author .

Example: Retired officers retain access to all of the university's educational and recreational facilities (Columbia University, 1987, p. 54).

H. Personal letters, telephone calls, and other material that cannot be retrieved are not listed in References but are cited in the text .

Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas. . .

I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources. Multiple citations should be arranged as follows .

Examples:

- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

All references must be complete and accurate. Where possible the DOI for the reference should be included at the end of the reference. Online citations should include date of access. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

Journal Article

Gardikiotis, A., Martin, R., &Hewstone, M. (2004). The representation of majorities and minorities in the British press: A content analytic approach. *European Journal of Social Psychology*, 34 , 637-646. DOI: 10.1002/ejsp.221

Book

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.

Book with More than One Author

Natarajan, R., &Chaturvedi, R. (1983). *Geology of the Indian Ocean* . Hartford, CT: University of Hartford Press.
Hesen, J., Carpenter, K., Moriber, H., &Milsop, A. (1983). *Computers in the business world* . Hartford, CT: Capital Press. and so on.

The abbreviation *et al.* is not used in the reference list, regardless of the number of authors, although it can be used in the text citation of material with three to five authors (after the initial citation, when all are listed) and in all parenthetical citations of material with six or more authors.

Web Document on University Program or Department Web Site

Degelman, D., & Harris, M. L. (2000). *APA style essentials*. Retrieved May 18, 2000, from Vanguard University, Department of Psychology Website:
http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc_id=796

Stand-alone Web Document (no date)

Nielsen, M. E. (n.d.). *Notable people in psychology of religion*. Retrieved August 3, 2001, from <http://www.psywww.com/psyrelig/psyrelpr.htm>

Journal Article from Database

Hien, D., & Honeyman, T. (2000). A closer look at the drug abuse-maternal aggression link. *Journal of Interpersonal Violence*, 15, 503-522. Retrieved May 20, 2000, from ProQuest database.

Abstract from Secondary Database

Garritty, K., & Degelman, D. (1990). Effect of server introduction on restaurant tipping. *Journal of Applied Social Psychology*, 20, 168-172. Abstract retrieved July 23, 2001, from PsycINFO database.

Article or Chapter in an Edited Book

Shea, J. D. (1992). Religion and sexual adjustment. In J. F. Schumaker (Ed.), *Religion and mental health* (pp. 70-84). New York: Oxford University Press.

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- Black and white and colour photos - 300 dpi
- Graphs, drawings, etc - 800 dpi preferred; 600 dpi minimum
- Combinations of photos and drawings (black and white and colour) - 500 dpi

Appendix 2 – Author guidelines for International Psychogeriatrics

CAMBRIDGE | Instructions for Contributors

International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, "for debate" articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, "for debate" articles and book reviews, which are commissioned, contributions to *International Psychogeriatrics* are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal's Science Citation Index Impact Factor (2011) is 2.24. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. *International Psychogeriatrics* has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

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When submitting your manuscript you will need to supply:

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2. That the authors have had full control of all the primary data.

3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. **The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final.** The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager, Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: + 61 3 9816 0477. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Submission of papers reporting randomized controlled trials

In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In common with many leading medical journals *International Psychogeriatrics* has decided to follow this policy. Since 31 December 2006 we will not review any paper submitted to us reporting a randomized clinical trial unless the trial was registered in a public trial registry from the date it commenced recruitment or, if recruitment started before 30 November 2006, we require that the trial was registered no later than 30 November 2006. For further details on the reasons for this policy see the June 2006 editorial, Ames, D. (2006). Registration of Clinical Trials submitted for publication in *International Psychogeriatrics*. *International Psychogeriatrics*, 18, 191-193.

All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.

- a. A check list and flow chart in accordance with the CONSORT guidelines which can be found at <http://www.consort-statement.org>. Please send in the checklist as a supplementary file and include the flow chart as Figure 1 in the manuscript.
- b. The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper.
- c. The registration number of the trial and the name of the trial registry in which it was registered. Please add these to the last line of the paper's structured abstract. Trials that began enrolment of patients after 31 December 2006 must have been registered in a public trials registry at or before the onset of enrolment to be considered for publication in *International Psychogeriatrics*. Trials that began enrolment prior to 30 November 2006 must have been registered no later than that date. Our criteria for a suitable public trial registry are: free to access; searchable; identification of trials by unique number; free or minimal cost for registration; validation of registered information; inclusion of details to identify the trial and the investigator within the registered entry (including the status of the trial); research question; methodology; intervention; and funding and sponsorship disclosed.

Organization and style of research articles

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author's email address, telephone number, fax number and postal address must be clearly stated.

Abstract: Abstracts should be brief, structured and should incorporate the 4 sub-headings: background, method(s), results and conclusion(s). Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.

Key words: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

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Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d, η^2 , Cramers V, 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t, F, χ^2).

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For a journal article: **Smith, J., Jones, W. I. and Doe, J. T.** (1996). Psychogeriatrics for pleasure and profit: an expanding field. *International Journal of Unreproducible Results*, 3, 240–242. doi:12.3456/S123456789.

For a book: **Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V.** (2001). *Acute Confusional States*. New York: Cambridge University Press.

For a book chapter. **Park, K., Tiger, B. and Runn, F.** (1999). Psychogeriatrics in context. In G. Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260) Cambridge: Cambridge University Press.

Where an article or book chapter has more than six authors only the first author's name should be given followed by the words "et al."

For further examples of reference style see papers in recent issues of *International Psychogeriatrics*.

Figures/Tables: The manuscript should contain no more than five figures or tables. The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some colour to be printed in some issues but authors wishing to publish figures requiring colour to communicate the data may be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

Supplementary material: More detail about the submission of supplementary material is available below – see "Supplementary Material for online only publication" and "Instructions for contributors – Supplementary Material" in subsequent pages of this document.

Word limits: At present *International Psychogeriatrics* does not have a fixed word limit for articles, but because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Conflict of interest

Conflict of interest occurs when authors have interests that **might** influence their judgement inappropriately, regardless of whether that judgement is influenced inappropriately or not. *International Psychogeriatrics* aims to conform to the policies of the World Association of Medical Editors in regard to conflict of interest. For full details please see the website <http://www.wame.org/wamestmt.htm#fundres>. To this end all authors must disclose potential conflicts of interest so that others may be aware of their possible effects. Specifically, under the heading conflict of interest, all articles must detail:

The source(s) of financial support for the research (if none, write "none").

A description of any sponsor's role(s) in the research (e.g., formulation of research question(s), choice of study design, data collection, data analysis and decision to publish).

Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects of a drug made by *Bigpharma* which directly competes with another drug made by *Megadruga* declaration might say "Jane Smith has received research support and speaker's honoraria from *Bigpharma* and has received financial assistance from *Megadruga* to enable her attend conferences."

Appendix 3 – Systematic review proformas

Quality Criteria for Reviewing Methodology

Study being reviewed:

| | Criteria | Supporting evidence from paper | Judgement | | Score |
|---|--|--|--|---|-------|
| 1 | The assignment of subjects to treatment groups is randomised | | Well covered Adequately addressed Poorly addressed | Not addressed Not reported Not applicable | |
| 2 | An adequate concealment method is used | | Well covered Adequately addressed Poorly addressed | Not addressed Not reported Not applicable | |
| 3 | Outcome assessors are kept 'blind' about treatment allocation | | Well covered Adequately addressed Poorly addressed | Not addressed Not reported Not applicable | |
| 4 | The treatment and control groups are similar at the start of the trial (or any differences are controlled for) | | Well covered Adequately addressed Poorly addressed | Not addressed Not reported Not applicable | |
| 5 | What percentage of the individuals or clusters recruited into each arm of the study dropped out before the study was completed? | Total drop out: n= %= Intervention drop out: n= %= Control drop out: n= %= | Is the drop out equal across groups? Yes/No/N/A Is the total drop out 20% or less? Yes/No/N/A | | |
| 6 | All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis) | | Well covered Adequately addressed Poorly addressed | Not addressed Not reported Not applicable | |
| 7 | The study has adequate statistical power | | Appropriate power analysis reported: Yes/No Adequate statistical power achieved: Yes/No/N/A | | |

Quality Criteria for Reviewing Methodology

Study being reviewed:

NOTES

Judgement & Scoring

For each question in this section you should use one of the following to indicate how well it has been addressed in the study:

| | |
|---|-----------|
| • Well covered | Score = 2 |
| • Adequately addressed | 1 |
| • Poorly addressed | 0 |
| • Not addressed (i.e. not mentioned, or indicates that this aspect of study design was ignored) | 0 |
| • Not reported (i.e. mentioned, but insufficient detail to allow assessment to be made) | 0 |
| • Not applicable | 0 |

For Yes/No questions scores are: Yes = 1 No = 0

Criteria

1) If the description of randomisation is poor, the study should be given a lower quality rating. Processes such as alternate allocation, allocation by date of birth, or day of the week attending a clinic are not true randomisation processes and it is easy for a researcher to work out which patients received which treatment. These studies should therefore be classed as Controlled Clinical Trials rather than RCTs.

2) Allocation concealment refers to the process used to ensure that researchers are unaware which group patients are being allocated to at the time they enter the study. Research has shown that where allocation concealment is inadequate, investigators can overestimate the effect of interventions by up to 40%. Centralised allocation, computerised allocation systems, or the use of coded identical containers would all be regarded as adequate methods of concealment, and may be taken as indicators of a well conducted study. If the method of concealment used is regarded as poor, or relatively easy to subvert, the study must be given a lower quality rating, and can be rejected if the concealment method is seen as inadequate.

3) Blinding refers to the process whereby people are kept unaware of which treatment an individual patient has been receiving when they are assessing the outcome for that patient. It can be carried out up to three levels. Single blinding is where patients are unaware of which treatment they are receiving. In double blind studies neither the doctor nor the patient knows which treatment is being given. In very rare cases studies may be triple blinded, where neither patients, doctors, nor those conducting the analysis are aware of which patients received which treatment. The higher the level of blinding, the lower the risk of bias in the study.

4) Patients selected for inclusion in a trial must be as similar as possible. The study should report any significant differences in the composition of the study groups in relation to gender mix, age, stage of disease (if appropriate), social background, ethnic origin, or comorbid conditions. These factors may be covered by inclusion and exclusion criteria, rather than being reported directly. Failure to address this question, or the use of inappropriate groups, should lead to the study being downgraded.

5) The number of patients that drop out of a study should give concern if the number is very high. Conventionally, a 20% drop out rate is regarded as acceptable, but this may vary. Some regard should be paid to why patients dropped out, as well as how many. It should be noted that the drop out rate may be expected to be higher in studies conducted over a long period of time. A higher drop out rate will normally lead to downgrading, rather than rejection of a study.

6) In practice, it is rarely the case that all patients allocated to the intervention group receive the intervention throughout the trial, or that all those in the comparison group do not. Patients may refuse treatment, or contra indications arise that lead them to be switched to the other group. If the comparability of groups through randomisation is to be maintained, however, patient outcomes must be analysed according to the group to which they were originally allocated irrespective of the treatment they actually received. (This is known as intention to treat analysis.) If it is clear that analysis was not on an intention to treat basis, the study may be included but should be evaluated as if it were a non-randomised cohort study.

Quality Criteria for Reviewing Congruence

Study being reviewed:

| 1) Do the authors report that the intervention was specifically designed with the intent of affecting this aspect of caregiver burden? | |
|---|--|
| Psychological wellbeing | Yes / No. Give supporting details from paper |
| Relationship between caregiver & care recipient | Yes / No. Give supporting details from paper |
| Physical health | Yes / No. Give supporting details from paper |
| Finances | Yes / No. Give supporting details from paper |
| Social life | Yes / No. Give supporting details from paper |

Quality Criteria for Reviewing Congruence

Study being reviewed:

| 2) Do the authors explicitly report a reasonable theoretical explanation or mechanism to suggest how the intervention would affect this aspect of caregiver burden? | |
|--|--|
| Psychological wellbeing | Yes / No. Give supporting details from paper |
| Relationship between caregiver & care recipient | Yes / No. Give supporting details from paper |
| Physical health | Yes / No. Give supporting details from paper |
| Finances | Yes / No. Give supporting details from paper |
| Social life | Yes / No. Give supporting details from paper |

| 3) Did the intervention have significantly reduce ZBI burden scores? | |
|---|-----------|
| Overall ZBI | Yes / No. |

Appendix 4 – SDCRN adoption approval

Psychiatry of Old Age
Murray Royal Hospital
Muirhall Road
Perth
PH2 7BH
Telephone Number: 01738 562322
Fax Number: 01738 562481



Louise Roach
Department of Clinical Psychology
Stratheden Hospital
Cupar
KY15 5RR

Our Ref
Enquiries to
Direct Line
E mail

NAN 18
Philip Brown, Administrator
01738 562322
philipbrown1@nhs.net

20th September, 2011

Dear Ms Roach

We have considered your study '**Dysfunctional Thought Processes in Dementia Caregivers**' for adoption to the Scottish Dementia Clinical Research Network.

We have pleasure in informing you that the network has approved adoption of your study, subject to an acceptable ethical approval, for the following support:

- Access to carer data

Please let me know when you require the data. We wish you every success in your project.

We would like to include a brief summary of your study and contact details on our website. Please let me know if this is not acceptable.

Please do not hesitate to contact me for further clarification and assistance when the time arises at emma.law@nhs.net.

Kind regards.

Yours sincerely

EMMA LAW
Manager
Scottish Dementia Clinical Research Network

Appendix 5 – Information sheet for SDCRN participants

Participant Information Sheet for recruitment through the Scottish Dementia Clinical Research Network



PARTICIPANT INFORMATION SHEET

Caring for someone with dementia: relationships between thoughts and emotions about caregiving

Information about the Research

My name is Louise Roach and I am undertaking a study as part of my Professional Doctorate in Clinical Psychology. I would like to invite you to take part in my research study looking at the relationships between thoughts and emotions about caring for someone with dementia. However, before you decide to do so, I need to be sure that you understand the purpose of the research and what participation would involve. The following information is provided to help you to decide whether you wish to take part. Please read the information carefully. If you want to, please discuss it with others including your friends and family.

Why have I been invited to take part?

You have been invited to join this study because you have registered with the Scottish Dementia Clinical Research Network as a caregiver of someone with dementia, who would be interested in participating in research.

What is the purpose of the research?

Previous research has suggested that people who care for someone with dementia are vulnerable to feeling guilty or low in mood. They may have thoughts about caregiving which make them feel worse. However, we do not have reliable ways of measuring these emotions or thoughts. This makes it hard to evaluate whether or not interventions designed to help support caregivers are effective. I would like to better understand the relationships between emotions and thoughts in relation to caring for someone with dementia. This will help researchers and clinicians to design and evaluate better interventions to help support caregivers to manage their emotions when caring for someone with dementia.

Do I have to take part?

No, it is up to you to decide. If you wish to take part, please complete the consent form and questionnaire. Even if you have started to fill in the questionnaire, you can stop taking part at any time or choose not to return it. Your decision whether or not to participate will not affect the health care you or the person with dementia receive.

What will I have to do if I take part?

If you take part, you will be required to complete the consent form and questionnaire, which are enclosed with this information sheet. Please complete and return them to me in the FREEPOST envelope as soon as possible. The questionnaire should take about 30 minutes to complete. If you would prefer to complete it over the phone, please telephone me on 01334 696336 to arrange that. In 3 months time, we will send you a reminder letter and questionnaire. If you do not wish to take part at this time, please ignore this letter.

Is there anything I should be concerned about if I take part?

The questionnaire asks questions about your current emotions and thoughts in relation to caring for someone with dementia. This may be upsetting for you. If you think answering the questions might upset you then you may choose not to take part. If the questionnaire causes you to become worried about your

Participant Information Sheet for recruitment through the Scottish Dementia Clinical Research Network

emotional wellbeing, please contact your GP. You may also find it helpful to contact the Alzheimer Scotland **freephone 24 hour dementia helpline** on **0808 808 3000**.

What are the possible benefits of taking part?

The study is not intended to benefit you personally. However, the information you give us will help researchers and clinicians to understand the relationships between emotions and thoughts in relation to caring for someone with dementia. This will help us to design and evaluate interventions to help support caregivers to manage their emotions when caring for someone with dementia.

What happens at the end of the research?

Once you have completed the questionnaire and returned it sealed in the FREEPOST envelope provided, the data from the questionnaires will be entered on to secure NHS computers for analysis. This data **does not** include your name or any personally identifiable information. The questionnaires will be kept in a locked NHS filing cabinet. The questionnaires **do not** include your name or any personally identifiable information. All data will be retained for 5 years after the end of the project, in accordance with research standards. If you request one, you will be posted a summary of the research findings at the end of the project, in summer 2013.

Will it be kept confidential?

Yes – all information collected will be kept strictly confidential, in accordance with NHS Fife policies. It will not be possible to identify you from your answers on the questionnaire.

Who is organising and paying for the research?

It is being organised by the University of Edinburgh and NHS Fife. I am doing this research as part of my Professional Doctorate training in Clinical Psychology.

Who has reviewed this study?

The South East Scotland Research Ethics Committee 1, which has responsibility for scrutinising all proposals for medical research on humans in South East Scotland, has examined the proposal. The committee has raised no objections from the point of view of medical ethics. It is a requirement that the records in this research are available for scrutiny by monitors from NHS Fife. Their role is to check that research is properly conducted and the interests of those taking part are adequately protected.

What if there is a problem?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint. You have the right to seek any resulting compensation through the University of Edinburgh who are acting as the research sponsor. Details about this are available from the research team.

How can I find out more?

If you have any questions about the study, please contact me and I will be happy to speak to you: Louise Roach, NHS Fife on 01334 696336 or email louise.roach@nhs.net. If you would prefer, you can also contact Tara Graham, NHS Fife who is independent of the research team on 01334 696336 or taragraham@nhs.net. If you wish to make a comment about the conduct of the research please contact: Dr Kathryn Quinn, NHS Fife on 01334 696336 or email kathrynquinn@nhs.net.

Thank you for taking the time to read this information sheet and for considering taking part in my study.

If you have a concern about dementia and wish to speak to someone, please call Alzheimer Scotland's 24 hour FREE helpline on:

0808 808 3000

Appendix 6 – Consent form



CONSENT FORM

Caring for someone with dementia: relationships between thoughts and emotions about caregiving

Please initial each box and sign at the bottom of the page

1. I confirm that I have read and understood the information sheet dated 21/11/11 (Version 6) for the above study. I have had the opportunity to consider the information, and to contact relevant staff within NHS Fife to ask questions, if I wished to do so. Any questions that I asked have been answered satisfactorily.

☐

2. I understand that my participation is voluntary. I understand that the care that I receive, and the care of the person with dementia whom I care for, will not be affected by my decision to take part in this study.

☐

3. I understand that the data gathered in this study will be anonymised, and stored securely on NHS Fife premises for 5 years, in accordance with best research practice.

☐

4. I agree to take part in the above study

☐

Your name

Date


Your signature

Consent Form

Version 1 – 21/11/11


Would you like to receive a summary of the findings of this study when it is completed (summer 2013)?

No ☐

Yes ☐  Please complete your name and address in the space below:

I would like to write to your GP to tell them that you have taken part in this study. This will not affect the care that you receive. I will not give them details of your answers on the questionnaire. Are you happy for me to contact your GP?

No ☐

Yes ☐  Please complete your name, date of birth and address, and your GP's name and address in the space below:

Appendix 7 – Information sheet for non-SDCRN participants

Generic Participant Information Sheet



PARTICIPANT INFORMATION SHEET

Caring for someone with dementia: relationships between thoughts and emotions about caregiving

Information about the Research

My name is Louise Roach and I am undertaking a study as part of my Professional Doctorate in Clinical Psychology. I would like to invite you to take part in my research study looking at the relationships between thoughts and emotions about caring for someone with dementia. However, before you decide to do so, I need to be sure that you understand the purpose of the research and what participation would involve. The following information is provided to help you to decide whether you wish to take part. Please read the information carefully. If you want to, please discuss it with others including your friends and family.

Why have I been invited to take part?

You have been invited to join this study because you care for somebody with dementia.

What is the purpose of the research?

Previous research has suggested that people who care for someone with dementia are vulnerable to feeling guilty or low in mood. They may have thoughts about caregiving which make them feel worse. However, we do not have reliable ways of measuring these emotions or thoughts. This makes it hard to evaluate whether or not interventions designed to help support caregivers are effective. I would like to better understand the relationships between emotions and thoughts in relation to caring for someone with dementia. This will help researchers and clinicians to design and evaluate better interventions to help support caregivers to manage their emotions when caring for someone with dementia.

Do I have to take part?

No, it is up to you to decide. If you wish to take part, please complete the consent form and questionnaire. Even if you have started to fill in the questionnaire, you can stop taking part at any time or choose not to return it. Your decision whether or not to participate will not affect the health care you or the person with dementia receive.

What will I have to do if I take part?

If you take part, you will be required to complete the consent form and questionnaire, which are enclosed with this information sheet. Please complete and return them to me in the FREEPOST envelope as soon as possible. The questionnaire should take about 30 minutes to complete. If you would prefer to complete it over the phone, please telephone me on 01334 696336 to arrange that.

Is there anything I should be concerned about if I take part?

The questionnaire asks questions about your current emotions and thoughts in relation to caring for someone with dementia. This may be upsetting for you. If you think answering the questions might upset you then you may choose not to take part. If the questionnaire causes you to become worried about your emotional wellbeing, please contact your GP. You may also find it helpful to contact the Alzheimer Scotland **freephone 24 hour dementia helpline** on **0808 808 3000**.

*Generic Participant Information Sheet***What are the possible benefits of taking part?**

The study is not intended to benefit you personally. However, the information you give us will help researchers and clinicians to understand the relationships between emotions and thoughts in relation to caring for someone with dementia. This will help us to design and evaluate interventions to help support caregivers to manage their emotions when caring for someone with dementia.

What happens at the end of the research?

Once you have completed the questionnaire and returned it sealed in the FREEPOST envelope provided, the data from the questionnaires will be entered on to secure NHS computers for analysis. This data **does not** include your name or any personally identifiable information. The questionnaires will be kept in a locked NHS filing cabinet. The questionnaires **do not** include your name or any personally identifiable information. All data will be retained for 5 years after the end of the project, in accordance with research standards. If you request one, you will be posted a summary of the research findings at the end of the project, in summer 2013.

Will it be kept confidential?

Yes – all information collected will be kept strictly confidential, in accordance with NHS Fife policies. It will not be possible to identify you from your answers on the questionnaire.

Who is organising and paying for the research?

It is being organised by the University of Edinburgh and NHS Fife. I am doing this research as part of my Professional Doctorate training in Clinical Psychology.

Who has reviewed this study?

The South East Scotland Research Ethics Committee 1, which has responsibility for scrutinising all proposals for medical research on humans in South East Scotland, has examined the proposal. The committee has raised no objections from the point of view of medical ethics. It is a requirement that the records in this research are available for scrutiny by monitors from NHS Fife. Their role is to check that research is properly conducted and the interests of those taking part are adequately protected.

What is there is a problem?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint. You have the right to seek any resulting compensation through the University of Edinburgh who are acting as the research sponsor. Details about this are available from the research team.

How can I find out more?

If you have any questions about the study, please contact me and I will be happy to speak to you: Louise Roach, NHS Fife on 01334 696336 or email louise.roach@nhs.net. If you would prefer, you can also contact Tara Graham, NHS Fife who is independent of the research team on 01334 696336 or taragraham@nhs.net. If you wish to make a comment about the conduct of the research please contact: Dr Kathryn Quinn, NHS Fife on 01334 696336 or email kathrynquinn@nhs.net.

Thank you for taking the time to read this information sheet and for considering taking part in my study.

If you have a concern about dementia and wish to speak to someone, please call Alzheimer Scotland's 24 hour FREE helpline on:

0808 808 3000

Appendix 8 – Fife Carers' Centre newsletter advertisement



***Do you care for someone with
Dementia? If so would you like
to take part in a research
project?***

Louise Roach, a Trainee Clinical Psychologist with NHS Fife, is looking for people who are caring for someone with dementia to take part in a research project. The study will look at the relationships between thoughts and emotions about caring for someone with dementia.

Louise wants to understand more about the relationships between emotions and thoughts in relation to caring for someone with dementia. This will help researchers and clinicians who work with people affected by dementia to design and evaluate better interventions to help support caregivers to manage their emotions when caring for someone with dementia.

The study involves completing a set of questionnaires, which takes approximately 30 minutes. If you would like, you can request to receive a summary of the results when the project is completed.

For more information, or to request a questionnaire pack, please contact:

Louise Roach on 01334 696336 or at

louise.roach@nhs.net

You can also complete the questionnaire online at: www.survey.ed.ac.uk/caregiving

Appendix 9 – Ethical approval

South East Scotland Research Ethics Committee 01

Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

29 November 2011

Miss Louise Roach
NHS Fife
Department of Clinical Psychology
Lynebank Hospital, Halbeath Road
Dunfermline
KY11 4UW

Dear Miss Roach,

Study title: Dysfunctional Thought Processes in Dementia
Caregivers
REC reference: 11/SS/0070

Thank you for your letter of 21 November 2011, responding to the Committee's request for further information on the above research [and submitting revised documentation]. The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|---|---------|-------------------|
| Covering Letter | | 07 October 2011 |
| Covering Letter | | 21 November 2011 |
| GP/Consultant Information Sheets | 1.0 | 21 November 2011 |
| Investigator CV | | |
| Other: advert UK carers forum | 1.0 | 16 May 2011 |
| Other: advert reminder | 1.0 | 16 May 2011 |
| Other: Fife carers centre advert | 2.0 | 07 October 2011 |
| Other: approval in principle - SDCRN | | 20 September 2011 |
| Participant Consent Form | 1.0 | 21 November 2011 |
| Participant Information Sheet: Generic | 5.0 | 21 November 2011 |
| Participant Information Sheet: SDCRN | 6.0 | 21 November 2011 |
| Protocol | 7.0 | 07 October 2011 |
| Questionnaire | 7.0 | 21 November 2011 |
| REC application | | 18 October 2011 |
| Response to Request for Further Information | | 21 November 2011 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

| | |
|-------------------|---|
| 11/SS/0070 | Please quote this number on all correspondence |
|-------------------|---|

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Janet Andrews
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments [if final opinion was confirmed was given at a meeting]

*Copy to: Ms Lynn Morrice
Dr Amanda Wood, NHS Fife*

South East Scotland Research Ethics Committee 01

Attendance at Sub-Committee of the REC meeting

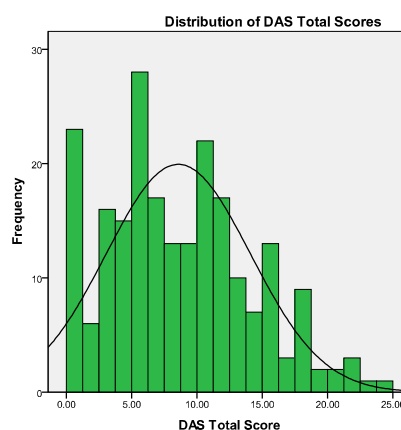
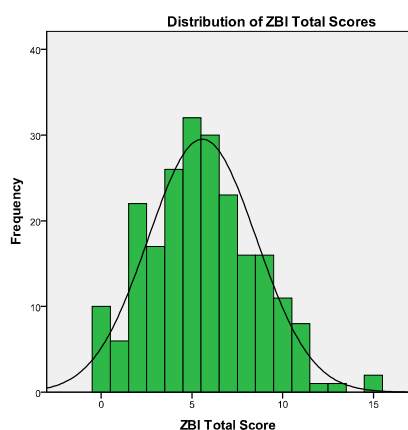
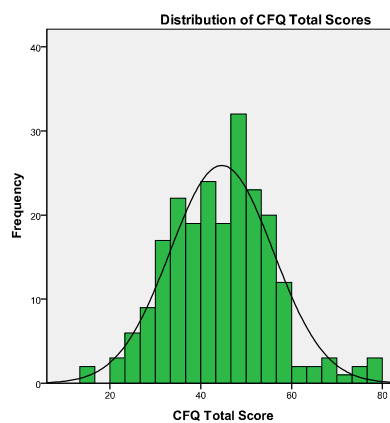
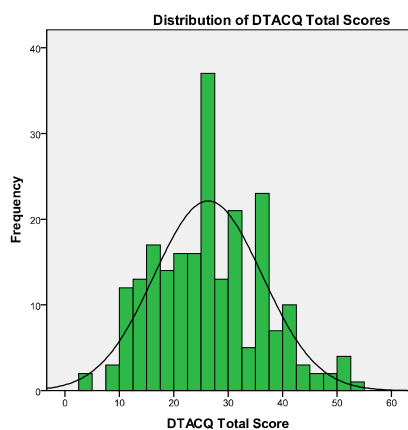
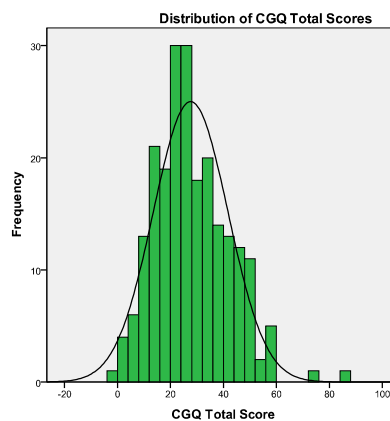
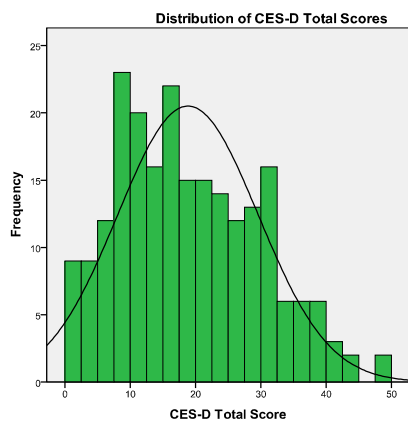
Committee Members:

| <i>Name</i> | <i>Profession</i> | <i>Present</i> | <i>Notes</i> |
|-------------------|-------------------------|----------------|--------------|
| Dr Janet Andrews | Associate Specialist | Yes | |
| Mr Lindsay Murray | Health & Safety Manager | Yes | |

Also in attendance:

| <i>Name</i> | <i>Position (or reason for attending)</i> |
|------------------|---|
| Mr Walter Hunter | Committee Coordinator |

Appendix 10 – Data distributions of key variables



Appendix 11 – Pattern matrix for five factor CGQ solution

Pattern Matrix– 5 factor solution for 22 item CGQ

| | Factor | | | | |
|----------|--------|-------|-------|-------|-------|
| | 1 | 2 | 3 | 4 | 5 |
| EM_CGQ1 | .004 | .194 | .202 | .318 | .098 |
| EM_CGQ2 | .805 | .061 | .061 | -.183 | .080 |
| EM_CGQ3 | -.020 | -.139 | -.006 | .016 | 1.044 |
| EM_CGQ4 | -.074 | -.088 | .022 | -.004 | .951 |
| EM_CGQ5 | .303 | .461 | -.148 | -.021 | .247 |
| EM_CGQ6 | -.166 | .398 | -.059 | .231 | -.146 |
| EM_CGQ7 | .059 | -.059 | .034 | .580 | .141 |
| EM_CGQ8 | .575 | .278 | -.126 | .090 | .038 |
| EM_CGQ9 | .137 | .652 | -.042 | .072 | .036 |
| EM_CGQ10 | 1.135 | -.300 | .022 | -.012 | -.093 |
| EM_CGQ11 | .882 | -.115 | .014 | .022 | -.091 |
| EM_CGQ12 | .397 | .126 | .199 | .144 | -.004 |
| EM_CGQ13 | .045 | .602 | .150 | -.085 | .085 |
| EM_CGQ14 | .712 | .100 | -.131 | .068 | -.016 |
| EM_CGQ15 | -.024 | .025 | .031 | .798 | .067 |
| EM_CGQ16 | -.012 | -.020 | -.068 | 1.014 | -.088 |
| EM_CGQ17 | -.060 | .107 | .530 | .127 | .119 |
| EM_CGQ18 | -.005 | -.072 | 1.015 | -.100 | -.019 |
| EM_CGQ19 | -.042 | -.014 | .912 | .011 | -.018 |
| EM_CGQ20 | .278 | .180 | .367 | .126 | -.055 |
| EM_CGQ21 | .007 | .857 | -.011 | -.105 | -.050 |
| EM_CGQ22 | -.131 | .846 | .023 | -.023 | -.174 |

Extraction Method: Principal Axis Factoring.

Rotation Method: Promax

Appendix 12 – Three factor solution for 16 item DTACQ

| Total Variance Explained – 3 factor solution for 16 item DTACQ | | | | | | | |
|--|---------------------|---------------|--------------|-------------------------------------|---------------|--------------|-----------------------------------|
| Factor | Initial Eigenvalues | | | Extraction Sums of Squared Loadings | | | Rotation Sums of Squared Loadings |
| | Total | % of Variance | Cumulative % | Total | % of Variance | Cumulative % | Total |
| 1 | 5.171 | 32.320 | 32.320 | 4.606 | 28.788 | 28.788 | 3.734 |
| 2 | 1.573 | 9.831 | 42.150 | .966 | 6.036 | 34.823 | 3.895 |
| 3 | 1.172 | 7.327 | 49.477 | .542 | 3.385 | 38.209 | 2.328 |
| 4 | 1.011 | 6.320 | 55.797 | | | | |
| 5 | .879 | 5.492 | 61.289 | | | | |
| 6 | .869 | 5.429 | 66.719 | | | | |
| 7 | .814 | 5.090 | 71.808 | | | | |
| 8 | .693 | 4.331 | 76.140 | | | | |
| 9 | .655 | 4.096 | 80.236 | | | | |
| 10 | .601 | 3.758 | 83.994 | | | | |
| 11 | .557 | 3.479 | 87.473 | | | | |
| 12 | .481 | 3.004 | 90.477 | | | | |
| 13 | .439 | 2.744 | 93.220 | | | | |
| 14 | .376 | 2.351 | 95.571 | | | | |
| 15 | .359 | 2.243 | 97.814 | | | | |
| 16 | .350 | 2.186 | 100.000 | | | | |

Extraction Method: Principal Axis Factoring.

Pattern Matrix– 3 factor solution for 16 item DTACQ

| | Factor | | |
|-----------|--------|-------|-------|
| | 1 | 2 | 3 |
| EM_DTCQ1 | .098 | .306 | .179 |
| EM_DTCQ2 | .617 | .016 | -.043 |
| EM_DTCQ3 | .314 | .462 | -.030 |
| EM_DTCQ4 | .619 | .231 | -.140 |
| EM_DTCQ5 | .668 | .089 | -.006 |
| EM_DTCQ6 | .083 | .618 | -.005 |
| EM_DTCQ7 | .227 | .504 | .003 |
| EM_DTCQ8 | -.019 | .629 | -.005 |
| EM_DTCQ9 | -.027 | .540 | .011 |
| EM_DTCQ10 | .252 | .366 | -.124 |
| EM_DTCQ11 | -.263 | .260 | .448 |
| EM_DTCQ12 | -.033 | .303 | .225 |
| EM_DTCQ13 | .027 | .060 | .689 |
| EM_DTCQ14 | .087 | .083 | .594 |
| EM_DTCQ15 | .733 | -.202 | .283 |
| EM_DTCQ16 | .075 | -.196 | .318 |

Extraction Method: Principal Axis Factoring.

Rotation Method: Promax

Appendix 13 – Pattern matrix for two factor 16 item DTACQ solution

Pattern Matrix– 2 factor solution for 16 item DTACQ

| | Factor | |
|-----------|--------|-------|
| | 1 | 2 |
| EM_DTCQ1 | .323 | .231 |
| EM_DTCQ2 | .627 | -.125 |
| EM_DTCQ3 | .687 | .011 |
| EM_DTCQ4 | .823 | -.196 |
| EM_DTCQ5 | .734 | -.083 |
| EM_DTCQ6 | .567 | .104 |
| EM_DTCQ7 | .627 | .067 |
| EM_DTCQ8 | .472 | .120 |
| EM_DTCQ9 | .397 | .118 |
| EM_DTCQ10 | .557 | -.095 |
| EM_DTCQ11 | -.102 | .550 |
| EM_DTCQ12 | .186 | .296 |
| EM_DTCQ13 | .013 | .708 |
| EM_DTCQ14 | .097 | .611 |
| EM_DTCQ15 | .531 | .136 |
| EM_DTCQ16 | -.107 | .272 |

Extraction Method: Principal Axis Factoring.

Rotation Method: Promax

Appendix 14 – Pattern matrix for two factor 15 item DTACQ solution

Pattern Matrix– 2 factor solution for 15 item DTACQ

| | Factor | |
|-----------|--------|-------|
| | 1 | 2 |
| EM_DTCQ2 | .647 | -.137 |
| EM_DTCQ3 | .664 | .049 |
| EM_DTCQ4 | .825 | -.176 |
| EM_DTCQ5 | .727 | -.060 |
| EM_DTCQ6 | .516 | .174 |
| EM_DTCQ7 | .611 | .090 |
| EM_DTCQ8 | .439 | .162 |
| EM_DTCQ10 | .528 | -.045 |
| EM_DTCQ11 | -.149 | .580 |
| EM_DTCQ13 | -.040 | .738 |
| EM_DTCQ14 | .069 | .609 |
| EM_DTCQ15 | .528 | .135 |
| EM_DTCQ1 | .313 | .233 |
| EM_DTCQ9 | .349 | .182 |
| EM_DTCQ12 | .155 | .322 |

Extraction Method: Principal Axis Factoring.

Rotation Method: Promax